

CHILD HEALTH ASSURANCE ACT OF 1979

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HEARINGS

BEFORE THE

SUBCOMMITTEE ON
HEALTH AND THE ENVIRONMENT

OF THE

COMMITTEE ON
INTERSTATE AND FOREIGN COMMERCE
HOUSE OF REPRESENTATIVES

NINETY-SIXTH CONGRESS

FIRST SESSION

ON

H.R. 2461 and H.R. 2159

BILLS TO STRENGTHEN AND IMPROVE THE EARLY AND
PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT PRO-
GRAM, AND FOR OTHER PURPOSES

H.R. 4053

A BILL TO STRENGTHEN AND IMPROVE MEDICAID SERVICES
TO LOW-INCOME CHILDREN AND PREGNANT WOMEN, AND FOR
OTHER PURPOSES

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American Academy of Pediatrics, Birt Harvey, M.D.
American Association of Psychiatric Services for Children (AAPSC), Lawrence Stone, M.D.
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Baltimore Welfare Rights Organization:
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 Pope, Paulette, chairperson.
Children's Defense Fund:
 Lazarus, Wendy, consultant.
 Weitz, program specialist/health.
Developmental Disabilities/Mental Health CHAP Coalition, Jewel Hamilton.
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 Heim, Richard, Director of Medicaid Finance, Health Care Financing Administration, Public Health Service.
 Hickman, William, Director, Division of Analysis and Evaluation, Medicaid Bureau, Health Care Financing Administration, Public Health Service.
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Michael A. Gelder & Associates, Inc., Michael A. Gelder, president.
National Health Law Program, David F. Chavkin, managing attorney.
Pennsylvania Department of Public Welfare, James McKittrick, program director, EPSDT, office of medical assistance.
Tri-City Citizens Union for Progress, Hazel Clarke, health coordinator.

CHILD HEALTH ASSURANCE ACT OF 1979

THURSDAY, JUNE 7, 1979

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT,
COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE,
Washington, D.C.

The subcommittee met, pursuant to notice, at 10 a.m., in room 2218, Rayburn House Office Building, Hon. Henry A. Waxman, chairman, presiding.

Mr. WAXMAN. The subcommittee will be in order.

Today the subcommittee begins the first of 2 days of hearings on legislation pending before the subcommittee to amend and revise the medicaid program to establish a program for the assurance of good health care to poor children.

CHAP, as this proposed program is commonly known, was considered in the last Congress in similar hearings. As a result of the testimony we received and the careful attention devoted to development of a bill by members of the subcommittee, a strong legislative proposal was reported by the Commerce Committee. That legislation was not acted on by the House despite what I believe was widespread support because time ran out before Congress could complete its full agenda of legislative business.

But the result of the actions of the last Congress has not been lost. We open hearings today on three measures—all similar in intent: to substantially improve health care for poor children and low-income pregnant women in this country. I believe all who examine the record will readily agree that each of the three bills before us today represents a substantial improvement over the legislation we began with when we opened our hearings in the last Congress. It is my hope that our deliberations this year will bring even further improvement.

Earlier this spring, this subcommittee heard convincing testimony concerning unmet health needs of children, particularly poor children, in this country. We received evidence of the impact on the future health of America's young which results from inadequate prenatal care, and even its complete absence, for their mothers. Today we begin the consideration in this Congress of how to address these problems effectively. Because we have three strong bills before us, each with varying approaches to certain phases of a CHAP program, we have the opportunity to receive from our witnesses advice on how to combine the best features of each to form a bill which can be widely supported and which can truly represent a long first step toward bringing good health to the children of America.

I want to comment that our ranking Republican member, Dr. Tim Lee Carter, has played a very active role in the debate on child health legislation and is an author of one of the CHAP bills before us.

Dr. Carter, do you have a statement?

Mr. CARTER. Yes, Mr. Chairman.

Mr. Chairman, I am very pleased that the subcommittee is turning to the issue of the child health assurance program this morning.

This legislation, which I introduced earlier this year, has been sponsored in similar form by several of my colleagues. Although there are three bills under consideration at this time, there is only one issue to be addressed. And that is the availability of quality health care for children in low-income families and for low-income pregnant women.

Those of us who were here in the last Congress will recall that the full committee reported a similar bill to the full House this past fall. Unfortunately, it failed to be considered before adjournment.

That Child Health Assurance Act in the 95th Congress was the result of extensive deliberation and, I submit, remains a good and a sensible approach to correcting some of the deficiencies of the existing early and periodic screening, diagnosis and treatment program.

In spite of present economic constraints, the need for enactment of a Child Health Assurance Act remains clear.

There is no greater potential benefit for our society than an effective and cost-efficient health program for children and pregnant women. The timely diagnosis and proper medical treatment of diseases saves money over the long run. Preventive health measures do work, and their value is particularly well-accepted for the youngsters and pregnant women to be served by CHAP.

If one doubts the value or need for the kinds of help CHAP would provide, he or she needs to see only one child brought to an emergency room at age 15 months in congestive heart failure because he was not diagnosed a few months earlier as iron deficient. A simple and routine blood test, a hematocrit would have identified this child as anemic when the disease still was asymptomatic. Relatively simple dietary treatment and the administration of therapeutic doses of iron would have prevented a life-threatening illness, family heartbreak, and an expensive hospitalization. Yet it is precisely these kinds of simple, routine procedures and care which CHAP would insure.

The child health assurance program will increase the emphasis on those simple but cost-effective services delivered on an ambulatory basis.

Although the CHAP program will require an initial outlay of funds, the decreased need for expensive high technology in-patient care ultimately will result in financial savings to the Government at both the Federal and State levels.

I look forward to hearing testimony from the distinguished groups gathered here today and those who will be here next week.

We have an opportunity to review our deliberations from the past Congress and to improve various provisions in the program as changes are shown to be advisable.

I believe that we will find that each of these bills—the one proposed by myself, the one proposed by my esteemed colleagues, and the one proposed by our good chairman on behalf of the administration—will prove to have their relative merits.

We need to listen carefully and to weigh the alternatives presented so that we can reach a reasonable consensus on meeting the basic goal we all share, to make quality health care available for low-income children and low-income pregnant women.

Although I believe that passage of this legislation is long overdue, we still can act now to achieve an ultimate victory of protecting and preserving the health of this Nation's most precious resource, our children.

Mr. WAXMAN. Thank you. Mr. Maguire, do you have a statement for the record?

Mr. MAGUIRE. Yes, thank you, Mr. Chairman.

Today and again next week our hearings will focus on CHAP, the child health assurance program. Just 3 weeks ago, at the child health oversight hearings on May 16, 1979, many of us heard testimony about serious deficiencies in the delivery of services and followup care to low income children under the existent early and periodic screening, diagnosis, and treatment program (EPSDT). As many of you know, the Child Health Assurance Act of 1978, which was reported out of the full committee on Interstate and Foreign commerce focused on providing comprehensive and preventive health care for poverty level children. Unfortunately, the bill was unable to be voted on before Congress adjourned. The 3 CHAP bills that have been introduced in 1979 clearly show the continuing determination of members of this committee and the administration to establish a viable program that will be truly responsive to the multifaceted continuing health needs of lower income children, adolescents and pregnant women. I am encouraged by the keen, widespread bipartisan support CHAP has received thus far. I know that all of us here today are looking forward to hearing testimony on the bills introduced by myself, by our distinguished subcommittee chairman, Mr. Waxman and by the ranking minority member of the subcommittee, Dr. Carter.

The testimony will guide us toward the most effective CHAP legislation—legislation designed to help maximize the normal, healthy development of our Nation's children. Each of us knows the famous quotation, "the child is father of the man." Surely it is imperative that we focus on ways of using our improved knowledge about health care so now we deliver appropriate health services to all children who are growing up today. Guarding physical and mental health during the formative years will help to insure a more positive environment for growth and development and this in turn will lay the groundwork for a healthier adult population for people of all socioeconomic levels.

Mr. WAXMAN. Thank you. Mr. Leland?

Mr. LELAND. Thank you, Mr. Chairman.

I take great pride in the seriousness this subcommittee has given to child and maternal health this year. One only has to spend 5

minutes walking through my district in Houston and then look up and over the oil company monolith skyline to understand that America has, until now, failed the citizenry. Clearly, one of every three of our children is walking a tight rope, lacking immunization, corrective health services and basic care that the majority in America take for granted. And the long-term costs in human suffering and dollars can no longer be tolerated.

Mr. Califano stated at a recent hearing—"CHAP should remain a hostage of Congress this year." I believe he is correct. This subcommittee has looked at, debated, and refined legislation over the past 2 years to meet this end. It is vital that we keep this goal, passage of "CHAP", a strong bill, foremost in our minds as we enter the hearing stage.

My staff and I have taken long and hard looks at the various proposals before us. Each one reflects sound thinking and sound planning. However, I come from a district where the EPSDT program was a mockery to the practice of medicine. We had doctors, proud inner-city pediatricians, who wished to participate in the program. Their good conscious led them to see many patients even though they were not reimbursed through this program. Why did the great State of Texas exclude them as private providers from this program? The issue then is how it gets done; what legislative mechanisms will be in place due to the enactment of our bill that will make this program work.

Clearly, the failing of EPSDT, in the part was in outreach. We must make it clear to recipients that their participation is important, to themselves and to the pride of this Nation. The key is in outreach. A caring phone call or visit from the provider; to promote immunization and preventive services; to offset the high risk of the alternate; crippling disease.

Services must be made available at day one of birth. Although infant mortality is still high in Houston, it was shocking 10 years ago. We had no regional neonatal intensive care units at that time. Prematurely born children had little hope of survival. Today, the picture is somewhat better. However, these neonatal units must be supported, and the States must be encouraged to give such treatment. We have proved that they are cost-effective in light of the short-term high operating costs. Yes, the CHAP bill must, by its very nature, emphasize ambulatory care, but this is not the entire picture. The 500 gram newborn does not benefit, yet, from ambulatory services. He or she benefits, society benefits, from getting him or her through and over those very difficult first months of life.

I am a futurist as well as a realist. All the doctoring in the world will do no good unless the nutritional needs of infants and children are met. The WIC programs, the food stamps programs, and others help in part. But adequate nutrition can only result from good dietary practices. And we have no national policy or even recommendations on how one goes about this. Obesity, iron deficiency anemia, and dental caries in childhood are rampant in this country and are preventable. And this primary prevention starts at home. I therefore, introduced yesterday with Mr. Maguire legislation, The Maternal and Childhood Nutritional Disorders Prevention and Information Act, as a complementary act to the CHAP legislation to refine, what little we know about nutrition and its

relationship to health and disease in childhood, and to provide treatment and outreach in our communities.

The CHAP legislation has the capacity to make major improvements in childhood health today. I believe my supporting legislation offers a solution to tomorrow's needs.

I ask members of this committee to keep this in mind, we are dealing with delivery of health and the prevention of long-term disease and paralysis, in this subcommittee. And we must support legislation that tells HEW specifically what mechanisms and systems we expect them to establish. The legislation must be extremely clear and extremely directive so that we need not return here 10 years hence to say "EPSDT and now CHAP failed our expectations."

Thank you, Mr. Chairman.

Mr. WAXMAN. Our first witness today is Dr. Karen Davis, Deputy Assistant Secretary for Planning and Evaluation, Department of Health, Education, and Welfare.

I am going to have to go to the Rules Committee to join Dr. Carter in pressing for some bills that have already passed the subcommittee. I am going to ask Congressman Maguire, who is the author of another CHAP bill before us, to take over the chair in my absence. Thank you for coming, and I look forward to a report on your testimony.

Without objection, the text of H.R. 2461, H.R. 2159, and H.R. 4053, and agency reports on H.R. 4053 will be printed at this point in the record.

[Testimony resumes on p. 87.]

[The bills and agency reports referred to follow:]

96TH CONGRESS
1ST SESSION

H. R. 2461

H.R. 2461, introduced by Mr. Maguire (for himself and Mr. Waxman on February 27, 1979

Cosponsored on May 3, 1979, by:

Mr. Lehman, Mr. Walgren, Mr. Murphy of Pennsylvania, Mr. Pepper, Mr. Conyers, Mr. Florio, Mr. Richmond, Mr. Corrada, Mr. Mitchell of Maryland, Mr. Moakley, Mr. Nolan, Mr. Beard of Rhode Island, Mr. Gore, Mr. Edwards of California, Mr. Kildee, Mr. Markey, Mr. Drinan, Mr. Downey, Mr. Dixon, Mr. Bedell, Mr. Scheuer, Mr. Gray, Mr. Bonior, Mr. Rowe, Mr. Stark, Mr. Weiss, and Mr. Gilman

Cosponsored on May 22, 1979, by:

Mr. Leland

A BILL

To strengthen and improve the early and periodic screening, diagnosis, and treatment program, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 SHORT TITLE; REFERENCE TO ACT

4 SECTION 1. (a) This Act may be cited as the "Child
5 Health Assurance Act of 1979".

6 (b) Whenever in this Act an amendment or repeal is
7 expressed in terms of an amendment to, or repeal of, a sec-
8 tion or other provision, the reference shall be considered to

1 be made to a section or other provision of the Social Security
2 Act.

3 PURPOSE

4 SEC. 2. The purpose of this Act is to modify the early
5 and periodic screening, diagnosis, and treatment program and
6 broaden medicaid eligibility—

7 (1) to introduce needy children into a health care
8 system within their community that will provide com-
9 prehensive, ongoing primary and preventive health
10 care;

11 (2) to increase the number of children eligible for
12 such care;

13 (3) to assure the continuity of care for a period
14 after a child would on account of income become ineli-
15 gible for medical care under the medicaid program;

16 (4) to assure that appropriate prenatal and post-
17 partum care is made available for needy pregnant
18 women;

19 (5) to increase immunization levels of children;
20 and .

21 (6) to provide further incentives to States to ar-
22 range for and encourage quality health care for
23 children.

1 MEDICAID ELIGIBILITY OF POOR CHILDREN, PREGNANT
2 WOMEN, AND HARD-TO-PLACE ADOPTED CHILDREN

3 SEC. 3. (a)(1) Section 1902(a)(10) is amended—

4 (A) by inserting “(i)” after “(A)” in subparagraph
5 (A);

6 (B) by striking out “clause (A)” and inserting in
7 lieu thereof “subparagraph (A)” each place it appears;

8 (C) by inserting after subparagraph (A) the follow-
9 ing new clauses:

10 “(ii) for making medical assistance available to
11 any individual who is under the age of 18 and (at the
12 option of the State) to any individual over the age of
13 17 and under the age of 21 (or within a reasonable
14 classification of such individuals), if the individual is a
15 member of a family—

16 “(I) which, on the basis of resources, either
17 is eligible for aid under the State plan approved
18 under part A of title IV or would be eligible for
19 aid under such State plan but for the fact that the
20 individual is not a dependent child under part A
21 of title IV, and

22 “(II) the income of which does not exceed
23 the higher of the income standard for such a
24 family to be eligible for any medical assistance
25 under the State plan or the national CHAP

1 income standard established under section
2 1902(d);

3 “(iii) for making medical assistance available to
4 any woman for a period of her pregnancy and for 60
5 days following the date of termination of her
6 pregnancy—

7 “(I) who, on the basis of resources, either is
8 eligible for aid under the State plan approved
9 under part A of title IV or would be eligible for
10 aid under such State plan if she had a dependent
11 child (as defined in part A of title IV) living with
12 her, and

13 “(II) whose income (including the income of
14 the family of which she is a member) does not
15 exceed the higher of the income standard for such
16 a woman to be eligible for any medical assistance
17 under the State plan or of the national CHAP
18 income standard established under section
19 1902(d);”.

20 (2) Section 1902(f) is amended (A) by striking out
21 “clause (10)(C)” and inserting in lieu thereof “paragraph
22 (10)(C)” each place it appears, and (B) by striking out
23 “clause (10)(A)” and inserting in lieu thereof “paragraph
24 (10)(A)(i)” each place it appears.

1 (3) Sections 1903(a)(1), 1903(f)(4)(C), and 1905(a) are
2 amended by striking out “section 1902(a)(10)(A)” and insert-
3 ing in lieu thereof “section 1902(a)(10)(A)(i)” each place it
4 appears.

5 (b)(1) Section 1905(a) is amended—

6 (A) by striking out “, except for section
7 406(a)(2),” in clause (ii);

8 (B) by striking out “or” at the end of clause (vi);

9 (C) by inserting “or” at the end of clause (vii);

10 (D) by inserting after and below clause (vii) the
11 following new clause:

12 “(viii) women during pregnancy and during the 60
13 days following the date of termination of pregnancy,”;

14 (E) by striking out “all of such cost—” in the
15 matter before paragraph (1) and inserting in lieu there-
16 of “all of such cost, or who are adopted children with
17 special needs (as defined in subsection (m))—”; and

18 (F) by adding at the end thereof the following
19 sentence: “An individual described in clause (i) of this
20 subsection shall be considered to have income insuffi-
21 cient to meet all of the cost of the care and services
22 described in this subsection if the income of his family
23 does not exceed the national CHAP income standard
24 established under section 1902(d), and an individual de-
25 scribed in clause (viii) of this subsection shall be con-

1 sidered to have income insufficient to meet all of the
2 cost of the care and services described in this subsec-
3 tion if the income of the individual (and of the family of
4 which the individual is a member) does not exceed the
5 national CHAP income standard established under sec-
6 tion 1902(d).”

7 (2) Section 1902(b) is amended by striking out para-
8 graph (2) and redesignating paragraphs (3) and (4) as para-
9 graphs (2) and (3), respectively.

10 (c) Section 1902 is amended by inserting after subsec-
11 tion (c) the following new subsection:

12 “(d)(1) For the purpose of establishing the eligibility of
13 and extent of medical assistance provided to certain children
14 and pregnant women, the Secretary shall establish by regula-
15 tion a national CHAP income standard.

16 “(2) The national CHAP income standard shall be two-
17 thirds of the nonfarm income official poverty line, as defined
18 by the Office of Management and Budget, revised annually in
19 accordance with section 624 of the Economic Opportunity
20 Act of 1964.

21 “(3) In applying the income standards established under
22 paragraph (2), each State shall take into consideration the
23 same income and expenses (including work-related expenses)
24 and disregard the same items of income in the same manner

1 as they would be taken into consideration or disregarded
2 under the State's plan under part A of title IV.”.

3 (d) Section 1905 is amended by adding after subsection
4 (l) the following new subsection:

5 “(m) The term ‘adopted child with special needs’ means
6 an individual who—

7 “(1)(A) is under the age of 18 or (B) (at the
8 option of the State) is over the age of 17 and under
9 the age of 21 (or within a reasonable classification of
10 such individuals);

11 “(2) has been placed for adoption;

12 “(3) was living in foster care immediately before
13 the date of his placement for adoption; and

14 “(4) on the date of his placement for adoption suf-
15 fered from a condition requiring continuing medical
16 care and services which condition the State determines
17 was a contributing factor to the difficulty of placing the
18 individual for adoption,

19 but only during the period beginning on the date of his place-
20 ment for adoption and ending on the date the individual turns
21 the age specified in paragraph (1) or, at the State's option
22 and if earlier, the date the State determines that the individ-
23 ual no longer requires the continuing care and services de-
24 scribed in paragraph (4).”.

1 (e) Section 1902(a)(17) is amended by inserting “,
2 except as provided under section 1902(d),” after “include
3 reasonable standards (which”.

4 REQUIRED SERVICES

5 SEC. 4. (a)(1) Section 1902(a)(13) is amended—

6 (A) by inserting at the end of subparagraph (A)
7 the following new clause:

8 “(iii) in the case of any individual under the
9 age of 21 who has received a timely periodic child
10 health assessment (as defined in section 1905(n)),
11 (I) for inclusion of all care and services, without
12 regard to any limitation in the amount, duration,
13 or scope of medical assistance, for which payment
14 is available under this title, whether or not under
15 the State plan for the State such care and serv-
16 ices are provided to individuals who have not
17 been so periodically assessed, and (II) for referral
18 for appropriate care and services not available
19 under this title; and”;

20 (B) by amending subparagraph (B) to read as
21 follows:

22 “(B) in the case of any individual described in
23 paragraph (10)(A), for the inclusion of at least the care
24 and services listed in paragraphs (1) through (5) of sec-
25 tion 1905(a), and”;

1 (C) by striking out "clauses" in subparagraph
2 (C)(i) and inserting in lieu thereof "paragraphs"; and

3 (D) by striking out "clauses numbered" in subparagraph
4 (C)(ii)(I) and inserting in lieu thereof "paragraphs".
5

6 (2) Section 1902(a)(14)(A)(i) is amended by striking out
7 "clauses" and inserting in lieu thereof "paragraphs".

8 (b) The clause (I) after subparagraph (C) of section
9 1902(a)(10) is amended by inserting "or services described in
10 paragraph (13)(A)(iii)" after "section 1905(a)".

11 (c) Section 1905(a)(4)(B) is amended to read as follows:
12 "; (B) child health assessments (as defined in subsection (n)),
13 diagnosis, treatment, referral, and medical case management
14 of individuals under the age of 21;".

15 (d) Section 1905(a)(4) is amended (1) by striking out
16 "and" before "(C)" and (2) by inserting "; (D) routine dental
17 care (as defined in subsection (o)) for individuals under the
18 age of 21; and (E) prenatal and postnatal services" before the
19 semicolon at the end thereof.

20 (e) Section 1905 is amended by adding after subsection
21 (m), added by section 3(d) of this Act, the following new sub-
22 sections:

23 "(n)(1) The term 'child health assessment' means such
24 an assessment provided in accordance with this subsection for
25 an individual under the age of 21 for such health problems

1 and at such periods as the Secretary shall specify in regula-
2 tions. Such assessments and other services described in sec-
3 tion 1905(a)(4)(B) shall be provided under a program (to be
4 known as the 'child health assurance program') to be devel-
5 oped by each State in accordance with this title.

6 “(2) Such assessments may only be provided under this
7 title by a health care provider who enters into a written
8 agreement (described in paragraph (3)) with the single State
9 agency responsible for administering or supervising the ad-
10 ministration of the State plan under this title.

11 “(3) The written agreement referred to in paragraph (2)
12 must provide, in accordance with standards established by
13 the Secretary, that the provider agrees as follows:

14 “(A) To provide timely and appropriate child
15 health assessments to individuals under the age of 21
16 and eligible under the State plan to receive such as-
17 sessments (such individuals hereinafter in this subsec-
18 tion referred to as 'eligible individuals').

19 “(B)(i) To provide directly to eligible individuals
20 whom it has assessed such basic diagnostic and treat-
21 ment services (including immunization against child-
22 hood diseases) as the Secretary shall specify in regula-
23 tions, or

24 “(ii) to provide to eligible individuals whom it has
25 assessed (I) timely referral to other health care provid-

1 ers for the provision of these basic diagnostic and
2 treatment services, and (II) followup services on a
3 timely basis to insure the provision of the services for
4 which such a referral has been made.

5 “(C)(i) To provide directly to eligible individuals
6 routine dental care (as defined in subsection (o)), or

7 “(ii) to provide to eligible individuals whom it has
8 assessed referral to a dentist, from a list provided by
9 the State agency of dentists participating in the child
10 health assurance program.

11 “(D)(i) To refer eligible individuals to appropriate
12 providers for any corrective treatment the need for
13 which is disclosed by an assessment but which is not
14 available directly from the provider, and (ii) to follow
15 up on a timely basis to assure the proper provision of
16 such treatment.

17 “(E) To take responsibility for the management of
18 the medical care of each eligible individual whom it
19 has assessed and to assure that child health assess-
20 ments are performed on a timely and periodic basis.

21 “(F) To be reasonably accessible on an ongoing
22 basis to eligible individuals whom it has assessed in
23 order to provide continuing medical care or to assure
24 the continuing availability of medical care and services.

1 “(G) To make such reports (i) to the State agency
2 as the agency determines to be necessary to assure
3 compliance with the requirements of the contract, and
4 (ii) to the Secretary as he determines to be necessary
5 to assure compliance with the requirements of the con-
6 tract.

7 In lieu of the followup services required under subparagraph
8 (B)(ii)(II) or (D)(ii), the written agreement with a health care
9 provider may provide that the provider will enter into a writ-
10 ten arrangement with an appropriate State or local public
11 agency or a nonprofit community-based agency or organiza-
12 tion, which arrangement and agency or organization meet
13 such standards as the Secretary may prescribe, whereby the
14 agency or organization provides for the timely followup serv-
15 ices required under such paragraph. Such agreement also
16 shall provide for the State agency providing the health care
17 provider with the names of dentists participating in the child
18 health assurance program in the area in which the provider is
19 located.

20 “(4) As used in this subsection and section 1902(a)(41),
21 the term ‘health care provider’ includes a private practition-
22 er, public health department, community health clinic or
23 center, primary care center, day care or headstart program,
24 rural health clinic, maternal and child health center, and a
25 school system.

1 “(5) Payment may be made under a State plan to a
2 health care provider for the provision of child health assess-
3 ments, and other medical care and services to children, under
4 an agreement described in paragraph (2) notwithstanding the
5 fact that the provider does not ordinarily bill other third-
6 party payers for the provision of such assessments, care, and
7 services.

8 “(o) The term ‘routine dental care’ means necessary di-
9 agnostic, preventive, restorative, and emergency dental serv-
10 ices, but only includes such orthodontics as the Secretary
11 determines by regulation to be appropriate for different age
12 groups for conditions causing major physical or psychological
13 handicap.”.

14 (f) Section 1903(i) is amended—

15 (1) by striking out the period at the end and in-
16 serting in lieu thereof “; or”, and

17 (2) by adding at the end thereof the following new
18 paragraph:

19 “(5) with respect to any amount expended for
20 dental screening apart from the provision of other rou-
21 tine dental care (as defined in section 1905(o)).”.

22 TREATMENT OF COPAYMENTS FOR MOTHERS AND CHAP

23 CHILDREN

24 SEC. 5. (a) Section 1902(a)(14) is amended—

1 (1) by striking out “and” at the end of subpara-
2 graph (A), and

3 (2) by striking out the semicolon at the end of
4 subparagraph (B) and inserting in lieu thereof “, and”,
5 and

6 (3) by adding after subparagraph (B) the following
7 new subparagraph:

8 “(C) in the case of individuals under the age of 21
9 who have received a timely child health assessment (as
10 defined in section 1905(n)), no enrollment fee, pre-
11 mium, deduction, cost sharing, or similar charge with
12 respect to any of the care and services listed in section
13 1905(a) will be imposed under the plan;”.

14 (b) Section 1902(a)(14)(A) is further amended by insert-
15 ing “, individuals described in paragraph (10)(A)(iii),” before
16 “and individuals with respect to whom there is being paid”.

17 CONTINUATION OF ELIGIBILITY

18 SEC. 6. Section 1902(e) is amended—

19 (1) by inserting “(1)” after “(e)”, and

20 (2) by adding at the end thereof the following new
21 paragraphs:

22 “(2) Notwithstanding any other provision of this title,
23 each State plan approved under this title must provide that
24 any individual under the age of 21 who, having had a timely
25 child health assessment (as defined in section 1905(n)), be-

1 comes ineligible (for a reason other than age) to receive care
2 and services provided under the State plan shall, nonetheless,
3 remain eligible for all such care and services provided under
4 the State plan to individuals who have had a timely child
5 health assessment until the end of the six-calendar-month
6 period beginning with the month following the month in
7 which the individual became ineligible.

8 “(3) Notwithstanding any other provision of this title,
9 each State plan approved under this title must provide that
10 any pregnant woman who is eligible, has applied for, and has
11 received medical assistance under this title and who becomes
12 ineligible for such assistance because of increased income or
13 resources shall, nonetheless, remain eligible for all such
14 medical assistance provided under the State plan until the
15 end of the 60-day period beginning on the date of the termi-
16 nation of her pregnancy.”.

17 **FEDERAL MATCHING FOR CHAP PROGRAM**

18 **SEC. 7. (a)** Section 1903(a) is amended—

19 (1) by inserting “subject to subsection (r),” in
20 paragraph (7) after “(7)”;

21 (2) by redesignating paragraph (7) as paragraph
22 (9); and

23 (3) by inserting after paragraph (6) the following
24 new paragraph:

“(7) an amount equal to the sum of (A) 75 per centum of sums expended during such quarter which are attributable to outreach and followup services provided by a State or local public agency under the child health assurance program under section 1905(n), (B) 90 per centum of sums expended during such quarter which are attributable to medical assistance (other than inpatient care and services but including outreach and followup services provided by approved nonprofit community-based organizations and followup services provided by health care providers, but not to exceed for such followup services a reasonable sum for each child provided services, which sum shall be determined by the Secretary taking into account the locality in which the services are provided) for the child health assurance program under section 1905(n), and (C) the product of (i) the lesser of (I) sum of the Federal medical assistance percentage plus 10 per centum, or (II) 90 per centum, and (ii) the sums expended during such quarter which are attributable to medical assistance for inpatient care and services under the child health assurance program under section 1905(n); plus”.

(b) Section 1902(a) is amended—

(1) by striking out “and” at the end of paragraph (39);

1 (2) by striking out the period at the end of para-
2 graph (40) and inserting in lieu thereof “; and”; and

3 (3) by adding at the end thereof the following new
4 paragraph:

5 “(41) provide that the State will develop, with
6 substantial public input, a plan for the implementation
7 of a child health assurance program described in sec-
8 tion 1905(n) which will meet the applicable level of ac-
9 ceptable performance established under section
10 1903(r)(1)(B) and which will (A) identify, and make
11 provision for written agreements described in section
12 1905(n)(3) with, all qualified health care providers on
13 such terms (including terms of prompt payment and
14 high reimbursement) as will reasonably be expected to
15 elicit their involvement in child health assessments, (B)
16 assure coordination between State and local agencies
17 participating in such assessments and federally funded
18 programs in the State providing health care services to
19 children, (C) assure (through the allocation of a reason-
20 able percentage of program funds and through the use,
21 whenever possible and in accordance with regulations
22 of the Secretary, of nonprofit community-based organi-
23 zations) the provision of outreach and followup services
24 to individuals and health care providers participating in
25 such program, and (D) describe measures to be taken

1 to reduce duplication of the well-child services provided
2 by other than a health care provider with an agree-
3 ment under section 1905(n) with those services pro-
4 vided under such program.”.

5 (c) Section 1903 is amended by adding after subsection
6 (q) the following new subsection:

7 “(r)(1)(A) In order to evaluate, and provide penalties
8 and bonuses with respect to, each State’s conduct of its child
9 health assurance program (described in section 1905(n)), the
10 Secretary shall establish by regulation performance standards
11 for child health assurance programs, which shall include
12 standards that measure—

13 “(i) the proportion of families of children eligible,
14 under subparagraph (A) or (B) of section 1902(a)(10),
15 for services under the State plan who are informed in a
16 timely manner of the availability of such services;

17 “(ii) the proportion of such children who are pro-
18 vided child health assessments (as defined in section
19 1905(n)) in a timely manner;

20 “(iii) the timely provision of medical care or serv-
21 ices the need for which is disclosed by a child health
22 assessment;

23 “(iv) the proportion of such children who are ap-
24 propriately immunized within a reasonable time follow-
25 ing their assessment; and

1 “(v) the compliance of health care providers with
2 the terms of agreements entered into pursuant to sec-
3 tion 1905(n).

4 “(B) In order to evaluate the performance of each
5 State’s child health assurance program for periods beginning
6 after April 1, 1980, with respect to the standards established
7 under subparagraph (A), the Secretary shall establish, and
8 provide timely notice to the State of, a level of acceptable
9 performance and a level of outstanding performance applica-
10 ble to the State’s program for each such period.

11 “(C) Each State shall cooperate with the Secretary by
12 providing appropriate documentation of the performance of
13 its child health assurance program in relation to the perform-
14 ance standards and levels of performance established under
15 subparagraphs (A) and (B).

16 “(2) The Secretary shall evaluate at least biannually the
17 performance of each State child health assurance program,
18 with respect to its meeting the levels of performance estab-
19 lished under paragraph (1)(B), and shall report his determina-
20 tion evaluating the State’s performance for a six-month
21 period to the State not later than six months after the end of
22 the period.

23 “(3)(A) If the Secretary determines, in such an evalua-
24 tion, that a State has failed to have a child health assurance
25 program which meets the applicable level of acceptable per-

1 formance established under paragraph (1)(B), the Secretary
2 shall notify the State of such failure and of the fact that the
3 amount otherwise required to be paid to the State, with re-
4 spect to each fiscal quarter beginning after the date of the
5 notification, pursuant to paragraphs (2), (3), (4), and (8) of
6 subsection (a) for administration of the State plan shall,
7 except as provided in subparagraphs (B) and (C), be reduced
8 by 20 percent of that amount until the State shows to the
9 satisfaction of the Secretary that the failure with respect to
10 which the reduction applies has been corrected.

11 “(B) If the Secretary is satisfied that a State intends to
12 correct a failure established under subparagraph (A), he may
13 withhold the imposition of a reduction under such subpara-
14 graph for a period of time (not exceeding six months) to allow
15 the State to fully achieve the applicable level of acceptable
16 performance. If, at the end of the period, the Secretary deter-
17 mines that the failure has been corrected, he may waive the
18 imposition of the reduction in whole or in part with respect to
19 the period.

20 “(C) Any State dissatisfied with a determination of the
21 Secretary under subparagraph (A) may, not later than sixty
22 days after the date it was notified of the determination, file a
23 petition with the Secretary for a review of the determination
24 in accordance with procedures established by the Secretary.
25 Such procedures shall provide that such review shall be con-

1 ducted by an impartial party and shall be completed, and
2 findings and a final determination made, not later than one
3 hundred and eighty days after the date the State filed its
4 petition for such review.

5 “(4) If the Secretary determines, in such an evaluation,
6 that a State’s child health assurance program has met its
7 applicable level of outstanding performance established under
8 paragraph (1)(B) for a calendar quarter, the Secretary shall
9 notify the State of such achievement and of the fact that the
10 amount paid under subsection (a)(8) with respect to the calen-
11 dar quarter shall be increased by an amount equal to 25 per-
12 cent of the remainder specified in such subsection.

13 “(5) The Secretary shall report to Congress, not later
14 than February 1 of each year (beginning with 1981), on
15 actual levels of performance of each State’s child health as-
16 surance program in relation to applicable levels of perform-
17 ance established under paragraph (1)(B).”.

18 STATE MAINTENANCE OF EFFORT REQUIREMENT

19 SEC. 8. Section 1903 is amended—

20 (1) by inserting “except as provided under subsec-
21 tion (s),” in subsection (a)(7), as added by section
22 7(a)(3), after “(7)”, and

23 (2) by adding after subsection (r), as added by sec-
24 tion 7(c), the following new subsection:

1 “(s) No State shall be entitled to payment of any
2 amount specified under subsection (a)(7) for a quarter begin-
3 ning during the four-year period beginning on the date of
4 enactment of the Child Health Assurance Act of 1979, if the
5 Secretary determines that the State has taken an action,
6 during such quarter or a previous quarter during the period,
7 which (1) reduces the standard of income for eligibility for
8 medical assistance for individuals under the age of twenty-
9 one below the applicable standards in existence on the date of
10 the enactment of such Act, or (2) reduces the amount, dura-
11 tion, or scope of medical assistance (other than inpatient care
12 and services) made available to individuals under the age of
13 twenty-one below the applicable medical assistance available
14 on such date of enactment.”

15 CHANGE IN EFFECTIVE DATE OF AID TO FAMILIES WITH
16 DEPENDENT CHILDREN PENALTY

17 SEC. 9. Section 403(g) is amended by striking out
18 “June 30, 1974” and inserting in lieu thereof “January 1,
19 1979”.

20 CLARIFICATION OF MEDICAID RESIDENCY REQUIREMENT

21 SEC. 10. (a) Section 1902(a)(16) is amended by striking
22 out “who are residents of the State” and inserting in lieu
23 thereof “who are determined to be living in the State”.

24 (b) Section 1902(b)(3) is amended by striking out “re-
25 sides in the State” and inserting in lieu thereof “lives in the

1 State (in accordance with standards established by the Secre-
2 tary)".

3 REPORT ON COORDINATION OF CHILD HEALTH PROGRAMS

4 SEC. 11. The Secretary of Health, Education, and Wel-
5 fare (hereinafter in this Act referred to as the "Secretary")
6 shall evaluate and shall submit to Congress, not later than
7 October 1, 1981, a report on—

8 (1) the coordination and integration of health care
9 services to children under the child health assurance
10 program and under title XIX of the Social Security
11 Act,

12 (2) the coordination and integration of health care
13 services to children under titles V and XIX of the
14 Social Security Act, and

15 (3) on actions undertaken, and recommendations
16 for actions that should be undertaken, by the States
17 and the Federal Government to improve the coordina-
18 tion and integration of child health services provided
19 under these titles and services provided under other
20 federally funded programs substantially involved in the
21 provision of health services to children.

22 STUDY AND DEMONSTRATION PROJECTS ON PROVIDER

23 PARTICIPATION IN CHAP PROGRAM

24 SEC. 12. (a) The Secretary, directly or through grants
25 to or contracts with public or private agencies or organiza-

1 tions, shall study and, to the extent he determines to be nec-
2 essary, conduct demonstration projects in order to evaluate
3 (1) the participation of health care providers in the child
4 health assurance programs established pursuant to section
5 1905(n) of the Social Security Act, and (2) methods of im-
6 proving their level of participation in these programs.

7 (b) The Secretary, directly or through grants to or con-
8 tracts with public or private agencies and organizations, shall
9 develop and carry out experiments and demonstration proj-
10 ects designed to determine the effect of payment on a capita-
11 tion basis for child health assessments and other services pro-
12 vided under child health assurance programs established pur-
13 suant to section 1905(n) of the Social Security Act upon the
14 level of participation and performance of such providers in
15 these programs.

16 (c) In the case of projects under this section, the Secre-
17 tary may waive compliance with the requirements of title
18 XIX of the Social Security Act, including those requirements
19 which relate to methods of payment for services provided, to
20 the extent and for the period he finds necessary to enable
21 States, agencies, or organizations to carry out such projects.
22 Costs incurred in such projects in excess of those which
23 would otherwise be reimbursed or paid under such title may
24 be reimbursed or paid to the extent that such waiver applies
25 to them (with such excess being borne by the Secretary,

1 under such terms and conditions as he may establish). Grants
2 and payments under contracts made for such projects may be
3 made in advance or by way of reimbursement, and in such
4 installments and on such conditions as the Secretary finds
5 necessary to carry out the purpose of this section.

6 (d) The Secretary shall submit to Congress, not later
7 than October 1, 1983, a report on the studies and projects
8 conducted under this section, including such findings, conclu-
9 sions, and recommendations as he deems appropriate.

10 (e)(1) The authority of the Secretary to enter into con-
11 tracts for studies, demonstration projects, and experiments
12 under this section shall be effective for any fiscal year only to
13 such extent or in such amounts as are provided in advance in
14 appropriation Acts.

15 (2) This section shall take effect on October 1, 1980.

16 CONTINUING MEDICAID ELIGIBILITY FOR CERTAIN INDI-
17 VIDUALS BY DISREGARDING CERTAIN INVOLUNTARY
18 INCREASES IN INCOME

19 SEC. 13. The next to last paragraph of subsection (a) of
20 section 1902 is amended by adding at the end the following
21 new sentence: "In the case of an individual who, for a month
22 after May 1979, was determined to be eligible for medical
23 assistance under the plan and was receiving a monthly insur-
24 ance benefit under title II of this Act or under the Railroad
25 Retirement Act of 1974, or compensation, dependency and

1 indemnity compensation, or a pension, under chapter 11, 13,
2 or 15 of title 38, United States Code (relating to veterans
3 and other persons), and who (but for this sentence) would
4 have become ineligible for such medical assistance in the sub-
5 sequent month because of an increase in the amount of such
6 benefit due to an increase in a cost-of-living index, or because
7 of an annual increase in the amount of such compensation or
8 pension becoming effective in such subsequent month, respec-
9 tively, for purposes of establishing the individual's eligibility
10 for medical assistance under the plan for such subsequent
11 month (and each month thereafter until the first month in
12 which the individual otherwise becomes ineligible for such
13 assistance) there shall not be included in the individual's
14 income any such increase in the amount of such benefit, com-
15 pensation, or pension which becomes effective in or after
16 such subsequent month."

17 CONTINUING MEDICAID ELIGIBILITY FOR CERTAIN
18 CHILDREN PLACED IN CERTAIN JUVENILE INSTITUTIONS

19 SEC. 14. (a) Section 1905(a) is amended by inserting
20 "and in subsection (p)" after "except as otherwise provided
21 in paragraph (16)" in the matter before subdivision (A).

22 (b) Section 1905, as amended by section 4(e) of this Act,
23 is further amended by adding after subsection (o) the follow-
24 ing new subsection:

1 “(p)(1) Notwithstanding subdivision (A) of subsection
2 (a), a State may include, in its plan for medical assistance
3 under this title, payments with respect to care and services
4 for an individual under 21 years of age while the individual is
5 an inmate of a public institution for juveniles if—

6 “(A) the individual, on the day before he became
7 an inmate of the institution, was eligible for medical
8 assistance under the State’s plan, or

9 “(B) the family in which the individual resided (on
10 the day before he became an inmate of the institution)
11 was eligible for medical assistance under the State’s
12 plan or would be eligible for medical assistance under
13 the State’s plan if the individual was still residing with
14 the family.

15 “(2) Notwithstanding paragraphs (10) and (14) of sec-
16 tion 1902(a), an individual for whom payment for care and
17 services is provided under paragraph (1) shall be treated
18 under the plan, with respect to the amount, duration, and
19 scope of medical assistance and to fees, premiums, deduc-
20 tions, cost sharing, and other charges—

21 “(A) in the case described in paragraph (1)(A), in
22 the same manner as the individual was treated on the
23 day before he became an inmate of the public institu-
24 tion, or, in the case of such an individual who was eli-
25 gible for but not provided medical assistance on that

1 day, would have been treated if provided medical as-
2 sistance on that day, and

3 “(B) in the case described in paragraph (1)(B), in
4 the same manner as the individual would otherwise be
5 treated if still residing with his family.”.

6 EFFECTIVE DATES

7 SEC. 15. (a)(1) Except as otherwise provided in this sec-
8 tion, the amendments made by this Act shall apply to medical
9 assistance provided, under a State plan approved under title
10 XIX of the Social Security Act, on and after April 1, 1980.

11 (2) In the case of any State plan, for medical assistance
12 under title XIX of the Social Security Act, which the Secre-
13 tary determines requires State legislation in order for the
14 plan to meet the additional requirements imposed by the
15 amendments made by this Act, the State plan shall not be
16 regarded as failing to comply with the requirements of such
17 title solely on the basis of its failure to meet these additional
18 requirements before the first day of the first calendar quarter
19 beginning after the close of the first regular session of the
20 State legislature that begins after the date of the enactment
21 of this Act.

22 (b) The amendment made by section 3(b)(1)(E) (relating
23 to establishing eligibility for hard-to-adopt children) shall
24 only apply to individuals placed for adoption on or after the
25 date of the enactment of this Act.

1 (c) The amendment made by section 9 (delaying the ef-
2 fective date of the aid to families with dependent children
3 penalty) shall apply to quarters beginning after June 30,
4 1974.

5 (d) Any individual under the age of 21 who has been
6 screened pursuant to section 1905(b)(4)(B) of the Social Se-
7 curity Act (as in effect on the date of the enactment of this
8 Act) on a date before the effective date of the amendments
9 made by section 4 of this Act shall, for purposes of sections
10 1902(a)(13)(A)(iii) and 1903(a)(7) of the Social Security Act
11 (as amended by this Act) be deemed, in accordance with reg-
12 ulations established by the Secretary, to have had a child
13 health assessment (as defined in section 1905(n) of the Social
14 Security Act, as amended by this Act) on that date.

15 (e) The amendments made by sections 10 (relating to
16 clarification of medical residency requirement) and 13 (relat-
17 ing to continuing medical eligibility for certain individuals by
18 disregarding certain involuntary increases in income) shall
19 take effect on the date of the enactment of this Act.

20 (f) The amendments made by section 14 shall apply to
21 medical assistance provided, under a State plan approved
22 under title XIX of the Social Security Act, on and after Oc-
23 tober 1, 1979.

1 (g) The Secretary shall first establish final regulations to
2 carry out the amendments made by this Act not later than
3 February 1, 1980.

96TH CONGRESS
1ST SESSION

H. R. 2159

To strengthen and improve the early and periodic screening, diagnosis, and treatment program, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 15, 1979

Mr. CARTER introduced the following bill; which was referred to the Committee on Interstate and Foreign Commerce

A BILL

To strengthen and improve the early and periodic screening, diagnosis, and treatment program, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 SHORT TITLE; REFERENCE TO ACT

4 SECTION 1. (a) This Act may be cited as the "Child
5 Health Assurance Act of 1979".

6 (b) Whenever in this Act an amendment or repeal is
7 expressed in terms of an amendment to, or repeal of, a sec-
8 tion or other provision, the reference shall be considered to

1 be made to a section or other provision of the Social Security
2 Act.

3 PURPOSE

4 SEC. 2. The purpose of this Act is to modify the early
5 and periodic screening, diagnosis, and treatment program and
6 broaden medicaid eligibility—

7 (1) to introduce needy children into a health care
8 system within their community that will provide com-
9 prehensive, ongoing primary and preventive health
10 care;

11 (2) to increase the number of children eligible for
12 such care;

13 (3) to assure the continuity of care for a period
14 after a child would on account of income become ineli-
15 gible for medical care under the medicaid program;

16 (4) to assure that appropriate prenatal and post-
17 partum care is made available for needy pregnant
18 women;

19 (5) to increase immunization levels of children;
20 and

21 (6) to provide further incentives to States to ar-
22 range for and encourage quality health care for
23 children.

1 MEDICAID ELIGIBILITY OF POOR CHILDREN, PREGNANT
2 WOMEN, AND HARD-TO-PLACE ADOPTED CHILDREN

3 SEC. 3. (a)(1) Section 1902(a)(10) is amended—

4 (A) by inserting “(i)” after “(A)” in subparagraph
5 (A);

6 (B) by striking out “clause (A)” and inserting in
7 lieu thereof “subparagraph (A)” each place it appears;

8 (C) by inserting after subparagraph (A) the follow-
9 ing new clauses:

10 “(ii) for making medical assistance available
11 to any individual who is under the age of 18 and
12 (at the option of the State) to any individual over
13 the age of 17 and under the age of 21 (or within
14 a reasonable classification of such individuals), if
15 the individual is a member of a family—

16 “(I) which, on the basis of resources,
17 either is eligible for aid under the State plan
18 approved under part A of title IV or would
19 be eligible for aid under such State plan but
20 for the fact that the individual is not a de-
21 pendent child under part A of title IV, and

22 “(II) the income of which does not
23 exceed the higher of the income standard for
24 such a family to be eligible for any medical
25 assistance under the State plan or the na-

1 tional CHAP income standard established
2 under section 1902(d);

3 “(iii) for making medical assistance available
4 to any woman for a period of her pregnancy and
5 for 60 days following the date of termination of
6 her pregnancy—

7 “(I) who, on the basis of resources,
8 either is eligible for aid under the State plan
9 approved under part A of title IV or would
10 be eligible for aid under such State plan if
11 she had a dependent child (as defined in part
12 A of title IV) living with her, and

13 “(II) whose income (including the
14 income of the family of which she is a
15 member) does not exceed the higher of the
16 income standard for such a woman to be eli-
17 gible for any medical assistance’ under the
18 State plan or of the national maternal
19 income standard established under section
20 1902(d);”.

21 (2) Section 1902(f) is amended (A) by striking out
22 “clause (10)(C)” and inserting in lieu thereof “paragraph
23 (10)(C)” each place it appears, and (B) by striking out
24 “clause (10)(A)” and inserting in lieu thereof “paragraph
25 (10)(A)(i)” each place it appears.

1 (3) Sections 1903(a)(1), 1903(f)(4)(C), and 1905(a) are
2 amended by striking out “section 1902(a)(10)(A)” and insert-
3 ing in lieu thereof “section 1902(a)(10)(A)(i)” each place it
4 appears.

5 (b)(1) Section 1905(a) is amended—

6 (A) by striking out “, except for section
7 406(a)(2),” in clause (ii);

8 (B) by striking out “or” at the end of clause (vi);

9 (C) by inserting “or” at the end of clause (vii);

10 (D) by inserting after and below clause (vii) the
11 following new clause:

12 “(viii) women during pregnancy and during the 60
13 days following the date of termination of pregnancy,”;

14 (E) by striking out “all of such cost—” in the
15 matter before paragraph (1) and inserting in lieu there-
16 of “all of such cost, or who are adopted children with
17 special needs (as defined in subsection (m))—”; and

18 (F) by adding at the end thereof the following
19 sentence: “An individual described in clause (i) of this
20 subsection shall be considered to have income insuffi-
21 cient to meet all of the cost of the care and services
22 described in this subsection if the income of his family
23 does not exceed the national CHAP income standard
24 established under section 1902(d), and an individual de-
25 scribed in clause (viii) of this subsection shall be con-

1 sidered to have income insufficient to meet all of the
2 cost of the care and services described in this subsec-
3 tion if the income of the individual (and of the family of
4 which the individual is a member) does not exceed the
5 national maternal income standard established under
6 section 1902(d).''.

7 (2) Section 1902(b) is amended by striking out para-
8 graph (2) and redesignating paragraphs (3) and (4) as para-
9 graphs (2) and (3), respectively.

10 (c) Section 1902 is amended by inserting after subsec-
11 tion (c) the following new subsection:

12 “(d)(1) For the purpose of establishing the eligibility of
13 and extent of medical assistance provided to certain children
14 and pregnant women, the Secretary shall establish by regula-
15 tion a national CHAP income standard and a national mater-
16 nal income standard.

17 “(2)(A) The national CHAP income standard shall be
18 \$2,400 for one individual, \$3,000 for a family of two, \$3,600
19 for a family of three, and \$4,200 for a family of four; shall be
20 increased by \$600 for each additional family member, over
21 four members and up to such family size as the Secretary
22 may establish by regulation; and shall be increased by such
23 amount for each additional family member above such speci-
24 fied family size as the Secretary establishes by regulation.

1 “(B) The national maternal income standard shall be
2 \$3,000 for a pregnant woman; shall be increased by \$600 for
3 each additional family member up to such family size as the
4 Secretary may establish by regulation; and shall be increased
5 by such amount for each additional family member above
6 such specified family size as the Secretary establishes by
7 regulation.

8 “(3) In applying the income standards established under
9 paragraph (2), each State shall take into consideration the
10 same income and expenses (including work-related expenses)
11 and disregard the same items of income in the same manner
12 as they would be taken into consideration or disregarded
13 under the State’s plan under part A of title IV.”.

14 (d) Section 1905 is amended by adding after subsection
15 (1) the following new subsection:

16 “(m) The term ‘adopted child with special needs’ means
17 an individual who—

18 “(1)(A) is under the age of 18 or (B) (at the
19 option of the State) is over the age of 17 and under
20 the age of 21 (or within a reasonable classification of
21 such individuals);

22 “(2) has been placed for adoption;

23 “(3) was living in foster care immediately before
24 the date of his placement for adoption; and

1 “(4) on the date of his placement for adoption suf-
2 fered from a condition requiring continuing medical
3 care and services which condition the State determines
4 was a contributing factor to the difficulty of placing the
5 individual for adoption,
6 but only during the period beginning on the date of his place-
7 ment for adoption and ending on the date the individual turns
8 the age specified in paragraph (1) or, at the State’s option
9 and if earlier, the date the State determines that the indi-
10 vidual no longer requires the continuing care and services
11 described in paragraph (4).”.

12 (e) Section 1902(a)(17) is amended by inserting “,
13 except as provided under section 1902(d),” after “include
14 reasonable standards (which”.

15 REQUIRED SERVICES

16 SEC. 4. (a)(1) Section 1902(a)(13) is amended—

17 (A) by inserting at the end of subparagraph (A)
18 the following new clause:

19 “(iii) in the case of any individual under the
20 age of 21 who has received a timely periodic child
21 health assessment (as defined in section 1905(n)),
22 (I) for inclusion of all care and services (other
23 than inpatient services in an institution for mental
24 diseases or in an intermediate care facility for the
25 mentally retarded), without regard to any limita-

1 tion in the amount, duration, or scope of medical
2 assistance, for which payment is available under
3 this title, whether or not under the State plan for
4 the State such care and services are provided to
5 individuals who have not been so periodically as-
6 sessed, and (II) for referral for appropriate care
7 and services not available under this title; and”;
8 (B) by amending subparagraph (B) to read as fol-
9 lows:

10 “(B) in the case of any individual described
11 in paragraph (10)(A), for the inclusion of at least
12 the care and services listed in paragraphs (1)
13 through (5) of section 1905(a), and ”;

14 (C) by striking out “clauses” in subparagraph
15 (C)(i) and inserting lieu thereof “paragraphs”; and

16 (D) by striking out “clauses numbered” in subpar-
17 agraph (C)(ii)(I) and inserting in lieu thereof “para-
18 graphs”.

19 (2) Section 1902(a)(14)(A)(i) is amended by striking out
20 “clauses” and inserting in lieu thereof “paragraphs”.

21 (b) Clause (I) of section 1902(a)(10) is amended by in-
22 serting “or services described in clauses (iii) and (iv) of para-
23 graph (13)(A)” after “section 1905(a)”.

24 (c) Section 1905(a)(4)(B) is amended to read as follows:
25 “; (B) child health assessments (as defined in subsection (n)),

1 diagnosis, treatment, referral, and medical case management
2 of individuals under the age of 21;”.

3 (d) Section 1905(a)(4) is amended (1) by striking out
4 “and” before “(C)” and (2) by inserting “; (D) routine dental
5 care (as defined in subsection (o)) for individuals under the
6 age of 21; and (E) prenatal and postnatal services” before the
7 semicolon at the end thereof.

8 (e) Section 1905 is amended by adding after subsection
9 (m), added by section 3(d) of this Act, the following new sub-
10 sections:

11 “(n)(1) The term ‘child health assessment’ means such
12 an assessment provided in accordance with this subsection for
13 an individual under the age of 21 for such health problems
14 and at such periods as the Secretary shall specify in regula-
15 tions. Such assessments and other services described in sec-
16 tion 1905(a)(4)(B) shall be provided under a program (to be
17 known as the ‘child health assurance program’) to be devel-
18 oped by each State in accordance with this title.

19 “(2) Such assessments may only be provided under this
20 title by a health care provider who enters into a written
21 agreement (described in paragraph (3)) with the single State
22 agency responsible for administering or supervising the ad-
23 ministration of the State plan under this title.

1 “(3) The written agreement referred to in paragraph (2)
2 must provide, in accordance with standards established by
3 the Secretary, that the provider agrees as follows:

4 “(A) To provide timely and appropriate child
5 health assessments to individuals under the age of 21
6 and eligible under the State plan to receive such as-
7 sessments (such individuals hereinafter in this subsec-
8 tion referred to as ‘eligible individuals’).

9 “(B)(i) To provide directly to eligible individuals
10 whom it has assessed such basic diagnostic and treat-
11 ment services (including immunization against child-
12 hood diseases) as the Secretary shall specify in regula-
13 tions, or

14 “(ii) To provide to eligible individuals whom it has
15 assessed (I) timely referral to other health care provid-
16 ers for the provision of these basic diagnostic and
17 treatment services, and (II) followup services to insure
18 the provision of the services for which such a referral
19 has been made.

20 “(C)(i) To provide directly to eligible individuals
21 routine dental care (as defined in subsection (o)), or

22 “(ii) To provide to eligible individuals whom it has
23 assessed information, from a list provided by the State
24 agency, on dentists participating in the child health
25 assurance program.

1 “(D)(i) To refer eligible individuals to appropriate
2 providers for any corrective treatment the need for
3 which is disclosed by an assessment but which is not
4 available directly from the provider, and (ii) to follow
5 up to assure the proper provision of such treatment.

6 “(E) To take responsibility for the management of
7 the medical care of each eligible individual whom it
8 has assessed and to assure that child health assess-
9 ments are performed on a timely and periodic basis.

10 “(F) To be reasonably accessible on an ongoing
11 basis to eligible individuals whom it has assessed in
12 order to provide continuing medical care or to assure
13 the continuing availability of medical care and services.

14 “(G) To make such reports (i) to the single State
15 agency administering or supervising the administration
16 of the plan as the agency determines to be necessary
17 to assure compliance with the requirements of the con-
18 tract, and (ii) to the Secretary as he determines to be
19 necessary to assure compliance with the requirements
20 of the contract.

21 In lieu of the followup services required under subparagraph
22 (B)(ii)(II) or (D)(ii), the written agreement with a health care
23 provider may provide that the provider will furnish the single
24 State agency that administers, or supervises the administra-
25 tion of, the State plan with such information as such agency

1 determines to be necessary to allow followup on the provision
2 of needed services. Such agreement also shall provide for the
3 State agency providing the health care provider with the
4 names of dentists participating in the child health assurance
5 program in the area in which the provider is located.

6 “(4) As used in this subsection and section 1902(a)(41),
7 the term ‘health care provider’ includes a private practi-
8 tioner, public health department, community health clinic or
9 center, primary care center, day care or headstart program,
10 rural health clinic, maternal and child health center, and a
11 school system.

12 “(5) Payment may be made under a State plan to a
13 health care provider for the provision of child health assess-
14 ments, and other medical care and services to children, under
15 an agreement described in paragraph (2) notwithstanding the
16 fact that the provider does not ordinarily bill other third-
17 party payers for the provision of such assessments, care, and
18 services.

19 “(o) The term ‘routine dental care’ means necessary di-
20 agnostic, preventive, restorative, and emergency dental serv-
21 ices, but only includes such orthodontics as the Secretary
22 determines by regulation to be appropriate for different age
23 groups for conditions causing major physical or psychological
24 handicap.”.

25 (f) Section 1903(i) is amended—

(1) by striking out the period at the end and inserting in lieu thereof “; or”, and

(2) by adding at the end thereof the following new paragraph:

“(5) with respect to any amount expended for dental screening apart from the provision of other routine dental care (as defined in section 1905(o)).”.

TREATMENT OF COPAYMENTS FOR MOTHERS AND CHILDREN

SEC. 5. (a) Section 1902(a)(14) is amended—

(1) by striking out “and” at the end of subparagraph (A), and

(2) by striking out the semicolon at the end of subparagraph (B) and inserting in lieu thereof “, and”, and

(3) by adding after subparagraph (B) the following new subparagraph:

“(C) in the case of individuals under the age of 21 who have received a timely child health assessment (as defined in section 1905(n)), no enrollment fee, premium, deduction, cost sharing, or similar charge with respect to any of the care and services listed in section 1905(a) will be imposed under the plan;”.

1 (b) Section 1902(a)(14)(A) is further amended by insert-
2 ing “, individuals described in paragraph (10)(A)(iii),” before
3 “and individuals with respect to whom there is being paid”.

4 CONTINUATION OF ELIGIBILITY

5 SEC. 6. Section 1902(e) is amended—

6 (1) by inserting “(1)” after “(e)”, and

7 (2) by adding at the end thereof the following new
8 paragraph:

9 “(2) Notwithstanding any other provision of this title,
10 each State plan approved under this title must provide that
11 any individual under the age of 21 who, having had a timely
12 child health assessment (as defined in section 1905(n)), be-
13 comes ineligible (for a reason other than age) to receive care
14 and services provided under the State plan shall, nonetheless,
15 remain eligible for all such care and services provided under
16 the State plan to individuals who have had a timely child
17 health assessment until the end of the 6-calendar-month
18 period beginning with the month following the month in which
19 the individual became ineligible.

20 “(3) Notwithstanding any other provision of this title,
21 each State plan approved under this title must provide that
22 any pregnant woman who is eligible, has applied for, and has
23 received medical assistance under this title and who becomes
24 ineligible for such assistance because of increased income or
25 resources shall, nonetheless, remain eligible for all such

1 medical assistance provided under the State plan until the
2 end of the 60-day period beginning on the date of the termi-
3 nation of her pregnancy.”.

4 FEDERAL MATCHING FOR CHAP PROGRAM

5 SEC. 7. (a)(1) Section 1905(b) is amended—

6 (A) by striking out “(1)” and “(2)” and inserting
7 in lieu thereof “(A)” and “(B)”, respectively;

8 (B) by inserting “(1)” after “(b)”; and

9 (C) by inserting at the end thereof the following
10 new paragraph:

11 “(2) The term ‘Federal CHAP percentage’ for any
12 State shall be a percentage equal to the lesser of—

13 “(A) the Federal medical assistance percentage
14 (determined under paragraph (1)) plus 25 percentage
15 points; or

16 “(B) 90 percent,

17 except that the Federal medical assistance percentage shall
18 be 100 percent with respect to amounts expended for medical
19 assistance for services which are received through an Indian
20 Health Service facility whether operated by the Indian
21 Health Service or by an Indian tribe or tribal organization (as
22 defined in section 4 of the Indian Health Care Improvement
23 Act).”.

1 (2) Section 1903(a)(1) is amended by striking out “sec-
2 tion 1905(b)” and inserting in lieu thereof “section
3 1905(b)(1)”.

4 (b) Section 1903(a) is amended—

5 (1) by inserting “subject to subsections (r) and
6 (s),” in paragraph (7) after “(7)”;

7 (2) by redesignating paragraph (7) as paragraph
8 (9); and

9 (3) by inserting after paragraph (6) the following
10 new paragraphs:

11 “(7) an amount equal to the Federal CHAP per-
12 centage (as defined in section 1905(b)(2)) of so much of
13 the sums expended during such quarter as are attribut-
14 able (A) to child health assessments (as defined in sec-
15 tion 1905(n)) or (B) to medical assistance for care and
16 services (other than inpatient care and services and
17 other than dental services that are not routine dental
18 services, as defined in section 1905(o)) provided to in-
19 dividuals who are under the age of 21 and who have
20 had a timely child health assessment; plus

21 “(8) an amount equal to 75 percent of so much of
22 the sums expended during each such quarter as are at-
23 tributable to costs of outreach and followup services for
24 individuals under the age of 21 and eligible for the as-

1 assessments and services described in section
2 1905(a)(4)(B); plus”.

3 (c) Section 1902(a) is amended—

4 (1) by striking out “and” at the end of paragraph
5 (39);

6 (2) by striking out the period at the end of para-
7 graph (40) and inserting in lieu thereof “; and”; and

8 (3) by adding at the end thereof the following new
9 paragraph:

10 “(41) provide that the State will develop (and
11 make available to the public for review and comment)
12 a plan for the implementation of a child health assur-
13 ance program described in section 1905(n) which will
14 meet the applicable level of acceptable performance es-
15 tablished under section 1903(r)(1)(B) and which will
16 (A) identify, and make provision for written agreements
17 described in section 1905(n)(3) with, all qualified health
18 care providers on such terms as will reasonably be ex-
19 pected to elicit their involvement in child health assess-
20 ments, (B) assure coordination between State and local
21 agencies participating in such assessments and feder-
22 ally funded programs in the State providing health care
23 services to children, and (C) assure the availability of
24 appropriate support services (including outreach and

1 followup services), in accordance with regulations of
2 the Secretary.”.

3 (d) Section 1903 is amended by adding after subsection
4 (q) the following new subsection:

5 “(r)(1)(A) In order to evaluate, and provide penalties
6 and bonuses with respect to, each State’s conduct of its child
7 health assurance program (described in section 1905 (n)), the
8 Secretary shall establish by regulation performance standards
9 for child health assurance programs, which shall include
10 standards that measure—

11 “(i) the proportion of families of children eligible,
12 under subparagraphs (A) or (B) of section 1902(a)(10),
13 for services under the State plan who are informed in a
14 timely manner of the availability of such services;

15 “(ii) the proportion of such children who are pro-
16 vided child health assessments (as defined in section
17 1905(n)) in a timely manner;

18 “(iii) the timely provision of medical care or serv-
19 ices the need for which is disclosed by a child health
20 assessment;

21 “(iv) the proportion of such children who are ap-
22 propriately immunized within a reasonable time follow-
23 ing their assessment; and

1 “(v) the compliance of health care providers with
2 the terms of agreements entered into pursuant to sec-
3 tion 1905(n).

4 “(B) In order to evaluate the performance of each
5 State’s child health assurance program for periods beginning
6 after April 1, 1979, with respect to the standards established
7 under subparagraph (A), the Secretary shall establish, and
8 provide timely notice to the State of, a level of acceptable
9 performance and a level of outstanding performance applica-
10 ble to the State’s program for each such period.

11 “(C) Each State shall cooperate with the Secretary by
12 providing appropriate documentation of the performance of
13 its child health assurance program in relation to the perform-
14 ance standards and levels of performance established under
15 subparagraphs (A) and (B).

16 “(2) The Secretary shall evaluate at least biannually the
17 performance of each State child health assurance program,
18 with respect to its meeting the levels of performance estab-
19 lished under paragraph (1)(B), and shall report his determina-
20 tion evaluating the State’s performance for a six-month
21 period to the State not later than six months after the end of
22 the period.

23 “(3)(A) If the Secretary determines, in such an evalua-
24 tion, that a State has failed to have a child health assurance
25 program which meets the applicable level of acceptable per-

1 formance established under paragraph (1)(B), the Secretary
2 shall notify the State of such failure and of the fact that the
3 amount otherwise required to be paid to the State, with re-
4 spect to each fiscal quarter beginning after the date of the
5 notification, pursuant to paragraphs (2), (3), (4), and (9) of
6 subsection (a) for administration of the State plan shall,
7 except as provided in subparagraphs (B) and (C), be reduced
8 by 20 percent of that amount until the State shows to the
9 satisfaction of the Secretary that the failure with respect to
10 which the reduction applies has been corrected.

11 “(B) If the Secretary is satisfied that a State intends to
12 correct a failure established under subparagraph (A), he may
13 withhold the imposition of a reduction under such subpara-
14 graph for a period of time (not exceeding six months) to allow
15 the State to fully achieve the applicable level of acceptable
16 performance. If at the end of the period, the Secretary deter-
17 mines that the failure has been corrected, he may waive the
18 imposition of the reduction in whole or in part with respect to
19 the period.

20 “(C) Any State dissatisfied with a determination of the
21 Secretary under subparagraph (A) may, not later than 60
22 days after the date it was notified of the determination, file a
23 petition with the Secretary for a review of the determination
24 in accordance with procedures established by the Secretary.
25 Such procedures shall provide that such review shall be con-

1 ducted by an impartial party and shall be completed, and
2 findings and a final determination made, not later than 180
3 days after the date the State filed its petition for such review.

4 “(4) If the Secretary determines, in such an evaluation,
5 that a State’s child health assurance program has met its
6 applicable level of outstanding performance established under
7 paragraph (1)(B) for a calendar quarter, the Secretary shall
8 notify the State of such achievement and of the fact that the
9 amount paid under subsection (a)(9) with respect to the calen-
10 dar quarter shall be increased by an amount equal to 25 per-
11 cent of the remainder specified in such subsection.

12 “(5) The Secretary shall report to Congress, not later
13 than February 1 of each year (beginning with 1980), on
14 actual levels of performance of each State’s child health as-
15 surance program in relation to applicable levels of perform-
16 ance established under paragraph (1)(B).”.

17 STATE MAINTENANCE OF EFFORT REQUIREMENT

18 SEC. 8. Section 1903 is amended—

19 (1) by inserting “except as provided under subsec-
20 tion (s),” in subsection (a)(7), as added by section
21 7(b)(3), after “(7)”, and

22 (2) by adding after subsection (r), as added by sec-
23 tion 7(d), the following new subsection:

24 “(s) No State shall be entitled to payment of any
25 amount specified under subsection (a)(7) for a quarter begin-

1 ning during the four-year period beginning on the date of
2 enactment of the Child Health Assurance Act of 1978, if the
3 Secretary determines that the State has taken an action,
4 during such quarter or a previous quarter during the period,
5 which (1) reduces the standard of income for eligibility for
6 medical assistance for individuals under the age of 21 below
7 the applicable standards in existence on the date of the enact-
8 ment of such Act, or (2) reduces the amount, duration, or
9 scope of medical assistance (other than inpatient care and
10 services) made available to individuals under the age of 21
11 below the applicable medical assistance available on such
12 date of enactment.”

13 REPEAL OF AID TO FAMILIES WITH DEPENDENT

14 CHILDREN PENALTY

15 SEC. 9. Section 403(g) is repealed.

16 CLARIFICATION OF MEDICAID RESIDENCY REQUIREMENT

17 SEC. 10. (a) Section 1902(a)(16) is amended by striking
18 out “who are residents of the State” and inserting in lieu
19 thereof “who are determined to be living in the State”.

20 (b) Section 1902(b)(2), as redesignated by section 3(b)(2)
21 of this Act, is amended by striking out “resides in the State”
22 and inserting in lieu thereof “lives in the State (in accordance
23 with standards established by the Secretary)”.

1 REPORT ON COORDINATION OF CHILD HEALTH PROGRAMS

2 SEC. 11. The Secretary of Health, Education, and Wel-
3 fare (hereinafter in this Act referred to as the "Secretary")
4 shall evaluate and shall submit to Congress, not later than
5 October 1, 1980, a report on—

6 (1) the coordination and integration of health care
7 services to children under titles V and XIX of the
8 Social Security Act, and

9 (2) on actions undertaken, and recommendations
10 for actions that should be undertaken, by the States
11 and the Federal Government to improve the coordina-
12 tion and integration of child health services provided
13 under these titles and services provided under other
14 federally funded programs substantially involved in the
15 provision of health services to children.

16 STUDY AND DEMONSTRATION PROJECTS ON PROVIDER

17 PARTICIPATION IN CHAP PROGRAM

18 SEC. 12. (a) The Secretary, directly or through grants
19 to or contracts with public or private agencies or organiza-
20 tions, shall study and, to the extent he determines to be nec-
21 essary, conduct demonstration projects in order to evaluate
22 (1) the participation of health care providers in the child
23 health assurance programs established pursuant to section
24 1905(n) of the Social Security Act, and (2) methods of im-
25 proving their level of participation in these programs.

1 (b) The Secretary directly or through grants to or con-
2 tracts with public or private agencies and organizations, shall
3 develop and carry out experiments and demonstration pro-
4 jects designed to determine the effect of payment on a capita-
5 tion basis for child health assessments and other services pro-
6 vided under child health assurance programs established pur-
7 suant to section 1905(n) of the Social Security Act upon the
8 level of participation and performance of such providers in
9 these programs.

10 (c) In the case of projects under this section, the Secre-
11 tary may waive compliance with the requirements of title
12 XIX of the Social Security Act, including those requirements
13 which relate to methods of payment for services provided, to
14 the extent and for the period he finds necessary to enable
15 States, agencies, or organizations to carry out such projects.
16 Costs incurred in such projects in excess of those which
17 would otherwise be reimbursed or paid under such title may
18 be reimbursed or paid to the extent that such waiver applies
19 to them (with such excess being borne by the Secretary,
20 under such terms and conditions as he may establish). Grants
21 and payments under contracts made for such projects may be
22 made in advance or by way of reimbursement, and in such
23 installments and on such conditions as the Secretary finds
24 necessary to carry out the purpose of this section.

1 (d) The Secretary shall submit to Congress, not later
2 than October 1, 1982, a report on the studies and projects
3 conducted under this section, including such findings, conclu-
4 sions, and recommendations as he deems appropriate.

5 CONTINUING MEDICAID ELIGIBILITY FOR CERTAIN INDIVIDUALS BY DISREGARDING CERTAIN INVOLUNTARY
6 INCREASES IN INCOME
7

8 SEC. 13. (a) The next to last paragraph of subsection (a)
9 of section 1902 is amended by adding at the end the follow-
10 ing new sentence: "In the case of an individual who, for a
11 month after May 1978, was determined to be eligible for
12 medical assistance under the plan and was receiving a
13 monthly insurance benefit under title II of this Act or under
14 the Railroad Retirement Act of 1974, or compensation, de-
15 pendency and indemnity compensation, or a pension, under
16 chapter 11, 13, or 15 of title 38, United States Code (relat-
17 ing to veterans and other persons) and who (but for this sen-
18 tence) would have become ineligible for such medical assist-
19 ance in the subsequent month because of an increase in the
20 amount of such benefit due to an increase in a cost-of-living
21 index, or because of an annual increase in the amount of such
22 compensation or pension becoming effective in such subse-
23 quent month, respectively, for purposes of establishing the
24 individual's eligibility for medical assistance under the plan
25 for such subsequent month (and each month thereafter until

1 the first month in which the individual otherwise becomes
 2 ineligible for such assistance) there shall not be included in
 3 the individual's income any such increase in the amount of
 4 such benefit, compensation, or pension which becomes
 5 effective in or after such subsequent month.”.

6 CONTINUING MEDICAID ELIGIBILITY FOR CERTAIN CHIL-
 7 DREN PLACED IN CERTAIN JUVENILE INSTITUTIONS

8 SEC. 14. (a) Section 1905(a) is amended by inserting
 9 “and in subsection (p)” after “except as otherwise provided
 10 in paragraph (16)” in the matter before subdivision (A).

11 (b) Section 1905, as amended by section 4(e) of this Act,
 12 is further amended by adding after subsection (o) the follow-
 13 ing new subsection:

14 “(p)(1) Notwithstanding subdivision (A) of subsection
 15 (a), a State may include, in its plan for medical assistance
 16 under this title, payments with respect to care and services
 17 for an individual under 21 years of age while the individual is
 18 an inmate of a public institution for juveniles if—

19 “(A) the individual, on the day before he became
 20 an inmate of the institution, was eligible for medical
 21 assistance under the State's plan, or

22 “(B) the family in which the individual resided (on
 23 the day before he became an inmate of the institution)
 24 was eligible for medical assistance under the State's
 25 plan or would be eligible for medical assistance under

the State's plan if the individual was still residing with the family.

“(2) Notwithstanding paragraphs (10) and (14) of section 1902(a), an individual for whom payment for care and services is provided under paragraph (1) shall be treated under the plan, with respect to the amount, duration, and scope of medical assistance and to fees, premiums, deductions, cost sharing, and other charges—

“(A) in the case described in paragraph (1)(A), in the same manner as the individual was treated on the day before he became an inmate of the public institution, or, in the case of such an individual who was eligible for but not provided medical assistance on that day, would have been treated if provided medical assistance on that day, and

“(B) in the case described in paragraph (1)(B), in the same manner as the individual would otherwise be treated if still residing with his family.”.

EFFECTIVE DATES

SEC. 15. (a)(1) Except as otherwise provided in this section, the amendments made by this Act shall apply to medical assistance provided, under a State plan approved under title XIX of the Social Security Act, on and after April 1, 1979.

(2) In the case of any State plan, for medical assistance under title XIX of the Social Security Act, which the Secre-

1 tary determines requires State legislation in order for the
2 plan to meet the additional requirements imposed by the
3 amendments made by this Act, the State plan shall not be
4 regarded as failing to comply with the requirements of such
5 title solely on the basis of its failure to meet these additional
6 requirements before the first day of the first calendar quarter
7 beginning after the close of the first regular session of the
8 State legislature that begins after the date of the enactment
9 of this Act.

10 (b) The amendment made by section 3(b)(1)(E) (relating
11 to establishing eligibility for hard-to-adopt children) shall
12 only apply to individuals placed for adoption on or after the
13 date of the enactment of this Act.

14 (c) The amendment made by section 9 (relating to repeal
15 of aid to families with dependent children penalty) shall apply
16 to quarters beginning after June 30, 1974.

17 (d) Any individual under the age of 21 who has been
18 screened pursuant to section 1905(b)(4)(B) of the Social Se-
19 curity Act (as in effect on the date of the enactment of this
20 Act) on a date before the effective date of the amendments
21 made by section 4 of this Act shall, for purposes of sections
22 1902(a)(13)(A)(iv) and 1903(a)(7) of the Social Security Act
23 (as amended by this Act) be deemed, in accordance with reg-
24 ulations established by the Secretary, to have had a child

1 health assessment (as defined in section 1905(n) of the Social
2 Security Act, as amended by this Act) on that date.

3 (e) The amendments made by section 14 shall apply to
4 medical assistance provided, under a State plan approved
5 under title XIX of the Social Security Act, on and after Oc-
6 tober 1, 1978.

7 (f) The Secretary shall first establish final regulations to
8 carry out the amendments made by this Act not later than
9 February 1, 1979.

96TH CONGRESS
1ST SESSION

H. R. 4053

To strengthen and improve medicaid services to low-income children and pregnant women, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MAY 10, 1979

Mr. WAXMAN introduced the following bill; which was referred to the Committee on Interstate and Foreign Commerce

A BILL

To strengthen and improve medicaid services to low-income children and pregnant women, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 SHORT TITLE; REFERENCE TO ACT

4 SECTION 1. (a) This Act may be cited as the "Child
5 Health Assurance Act or 1979".

6 (b) Whenever in this Act an amendment or repeal is
7 expressed in terms of an amendment to, or repeal of, a sec-
8 tion or other provision, the reference shall be considered to

1 be made to a section or other provision of the Social Security
2 Act.

3 PURPOSE

4 SEC. 2. The purpose of this Act is to broaden medicaid
5 eligibility for children and pregnant women, and to improve
6 the delivery of preventive and other health care services to
7 children under medicaid—

8 (1) to increase the number of needy children and
9 pregnant women eligible for medicaid coverage;

10 (2) to replace the early and periodic screening, di-
11 agnosis, and treatment program with a strengthened
12 child health assurance program:

13 (3) to encourage participation in the medicaid pro-
14 gram of providers willing to assume responsibility for
15 comprehensive, continuing primary and preventive
16 health care of individual children;

17 (4) to require more comprehensive medicaid cov-
18 erage of needed health services for eligible children;
19 and

20 (5) to provide incentives to States to arrange for
21 and encourage quality health care for children.

22 TITLE I—CHILD HEALTH ASSURANCE PROGRAM;

23 MEDICAID ELIGIBILITY OF POOR CHILDREN

24 MEDICAID ELIGIBILITY OF POOR CHILDREN

25 SEC. 101. (a)(1) Section 1902(a)(10)(A) is amended—

1 (A) by inserting the clause designation "(i)" after
 2 the clause designation "(A)", and

3 (B) by adding at the end the following:

4 "(ii) for making medical assistance available
 5 to any individual under the age of 18 (or, at the
 6 option of the State, to any individual under the
 7 age of 19, 20, or 21) whose resources (including
 8 the resources of his family) meet the resources
 9 test of eligibility for medical assistance under the
 10 State plan approved under this title applicable to
 11 a family with dependent children, and whose
 12 income either (I) meets the income test of eligibil-
 13 ity for medical assistance under such plan applica-
 14 ble to a family with dependent children or (II)
 15 does not exceed 55 per centum of the amount es-
 16 tablished for an individual or for a family of that
 17 size, as appropriate, by the income poverty guide-
 18 lines for the nonfarm population of the United
 19 States as prescribed by the Office of Management
 20 and Budget (and adjusted annually) pursuant to
 21 section 625 of the Economic Opportunity Act of
 22 1964;"

23 (2) Sections 1903(a)(1), 1903(f)(4)(C), and 1905(a) are
 24 amended by striking out "section 1902(a)(10)(A)" and insert-
 25 ing instead "section 1902(a)(10)(A)(i)" each place it appears.

1 (b)(1) Section 1902(b) is amended by striking out clause
 2 (2) and redesignating clauses (3) and (4) as clauses (2) and
 3 (3), respectively.

4 (2) Section 1905(a) is amended in clause (ii) by striking
 5 out “, except for section 406(a)(2),”.

6 (c) Section 1902(a)(17) is amended in clause (B) by in-
 7 serting immediately after “except for income and resources”
 8 the following: “or family composition”.

9 CHILD HEALTH ASSURANCE PROGRAM (CHAP)

10 SEC. 102. (a) Section 1902(a) is amended—

11 (1) by striking out “and” after paragraph (39),

12 (2) by striking out the period after paragraph (40)
 13 and inserting instead “; and” and

14 (3) by adding after paragraph (40) the following
 15 new paragraph:

16 “(41) provide for a child health assurance pro-
 17 gram in accordance with section 1913.”.

18 (b) Title XIX is amended by adding at the end thereof
 19 the following new section:

20 “CHILD HEALTH ASSURANCE PROGRAM (CHAP)

21 “SEC. 1913. A child health assurance program under
 22 this section shall meet the following requirements:

23 “(a)(1) The program must assure the availability, to
 24 each child eligible under section 1902(a)(13)(iii) to receive
 25 such services, of child health assessments in accordance with

1 this subsection, at such periods and including such services
2 and procedures appropriate for an individual of his age as the
3 Secretary shall specify in regulations, in order to determine
4 the child's health status and to identify health problems.

5 “(2) Child health assessments may be provided under
6 this subsection only by an eligible provider (as determined
7 under subsection (e)) who enters into a written agreement
8 with the single State agency (in accordance with standards
9 established by the Secretary) to do the following:

10 “(A) To provide timely and appropriate child
11 health assessments to individuals eligible under the
12 State plan to receive such assessments (hereinafter in
13 this section referred to as ‘eligible individuals’).

14 “(B)(i) To provide directly to eligible individuals
15 whom it has assessed such basic diagnostic and treat-
16 ment services (including immunization against child-
17 hood diseases) as the Secretary shall specify in regula-
18 tions, or

19 “(ii)(I) To refer eligible individuals whom it has
20 assessed promptly to other health care providers for
21 the provision of the basic diagnostic and treatment
22 services specified in clause (i), and (II) to provide to
23 such individuals followup services to insure the timely
24 and appropriate provision of the services for which
25 such a referral has been made, or to furnish to the

1 single State agency such information as that agency
2 determines to be necessary to allow followup on the
3 provision of needed services.

4 “(C) To make such reports as the single State
5 agency and the Secretary may require to assure com-
6 pliance with the written agreement and with the re-
7 quirements of this section.

8 “(3) The program must assure that the State agency
9 assumes responsibility for the management of the medical
10 care of each assessed child, including followup on the provi-
11 sion of needed care and services, and scheduling for and pro-
12 vision of subsequent periodic child health assessments, unless
13 the child health assessment provider or the continuing care
14 provider has assumed such responsibility.

15 “(b)(1) The program must provide for participation in
16 the program under this title by providers of continuing care
17 for children in accordance with this subsection.

18 “(2) Continuing care under this subsection may be pro-
19 vided by a qualified provider (as determined under subsection
20 (e)) who enters into a written agreement with the single
21 State agency to do the following with respect to a specific
22 eligible individual:

23 “(A) To provide child health assessments in ac-
24 cordance with subsection (a)(2)(A).

1 “(B) To provide continuing diagnosis and treat-
2 ment services in accordance with subsection (a)(2)(B)(i),
3 and to make all reports required pursuant to subsection
4 (a)(2)(C).

5 “(C) To manage the medical care of such individ-
6 ual to assure that all necessary medical services which
7 are provided under the State plan are made available
8 in a timely manner, and to assure that reassessments
9 are performed on a timely and periodic basis, as re-
10 quired by the Secretary in regulations.

11 “(D) To provide continuing primary and preven-
12 tive care (including such care and services as the Sec-
13 retary may specify in regulations), and to be reason-
14 ably available on a continuing basis for delivery of
15 services.

16 “(3) States shall make payments to continuing care pro-
17 viders for services provided pursuant to paragraph (2) in ac-
18 cordance with methods and standards meeting such require-
19 ments as the Secretary may by regulation provide. The Sec-
20 retary may establish minimum reimbursement levels (which
21 may be uniform nationally or may vary by State or region),
22 may permit or require payment based on a prospectively de-
23 termined capitation rate, and payment on a periodic basis,
24 and may permit or require other payment incentives.

1 “(c) The program must assure that the State agency (1)
2 assumes responsibility for assuring that all children of whom
3 it has knowledge eligible for services under the plan are in-
4 formed of the need for and availability of dental services, and
5 are referred to providers of such care and services on a
6 timely and periodic basis, and (2) will prepare a list of den-
7 tists providing services under the plan, which it shall update
8 regularly and provide at least annually to all such children.

9 “(d) The program must provide for outreach to individ-
10 uals eligible for assessments under this subsection. Outreach
11 under this subsection includes such activities as the Secretary
12 may permit or require, but must include identifying and locat-
13 ing families of eligible children and informing them of the
14 availability of assessments, continuing care, and other child
15 health services.

16 “(e)(1) Providers of child health assessment services
17 under subsection (a) and continuing care services under sub-
18 section (b) shall include primary health care centers funded
19 under the Public Health Service Act (including community
20 health centers and migrant health centers); maternal and
21 infant care projects and children and youth projects funded
22 under title V of the Social Security Act; facilities delivering
23 ambulatory health services operated by the Indian Health
24 Service; State health departments and other State and local
25 governmental entities; schools; rural health clinics; health

1 maintenance organizations; physicians; and such other pro-
 2 viders as may be specified by the Secretary in regulations.

3 “(2) The State agency shall enter into a written agree-
 4 ment under subsection (a) or (b) with any provider specified
 5 in paragraph (1) unless it reasonably determines with respect
 6 to a specific provider, in accordance with such standards and
 7 procedures as the Secretary may prescribe, that such provid-
 8 er will not satisfactorily provide the care and services re-
 9 quired under such subsection.

10 “(f) The Secretary may by regulation require that all
 11 providers of child health assessments and other ambulatory
 12 child health care services under this title (or all providers
 13 within reasonable classifications of such providers) submit
 14 uniform reports and use uniform claim forms.”.

15 ‘REQUIRED COVERAGE FOR CHILDREN

16 SEC. 103. (a) Section 1902(a)(13) is amended by insert-
 17 ing at the end of clause (A) the following new clause:

18 “(iii) in the case of any individual under the
 19 age of 18, (I) for inclusion of the care and serv-
 20 ices listed in clauses (1), (2), (3), (4)(B)(i), and (5)
 21 of section 1905(a) without limitation on the
 22 amount, duration, or scope of medical assistance,
 23 (II) for inclusion of the care and services listed in
 24 clause (4)(B)(ii) which may not be less in amount,
 25 duration and scope than minimum limits which

1 the Secretary may prescribe, and (III) for inclu-
 2 sion of the care and services listed in clause
 3 (4)(B)(iii) of section 1905(a), and”.

4 (b) Clause (I) of section 1902(a)(10) is amended by in-
 5 serting “and the making available of the services described in
 6 clause (iii) of paragraph (13)(A) to individuals meeting the
 7 requirements prescribed therein” after “section 1905(a)”.

8 (c) Section 1905(a)(4)(B) is amended to read as follows:
 9 “; (B) the following services for individuals under the age of
 10 18 (and, where the State exercises the option under section
 11 1902(a)(10)(B)(ii), to individuals under the age of 19, 20, or
 12 21): (i) child health assessment services and continuing care
 13 services provided in accordance with section 1913, immuni-
 14 zations, prescribed drugs and insulin, diagnosis and treatment
 15 of vision and hearing problems, including hearing aids and
 16 eyeglasses, (ii) ambulatory mental health services delivered in
 17 centers funded under the Community Mental Health Centers
 18 Act or meeting standards established by the Secretary in reg-
 19 ulations, and (iii) routine dental care and services (which shall
 20 include only diagnostic, preventive, restoration, and emer-
 21 gency dental services);”.

22 TREATMENT OF COPAYMENTS FOR CHILDREN

23 SEC. 104. (a) Section 1902(a)(14)(A) is amended by inserting
 24 immediately after “paragraph (10)(A)” the following: “, or

1 who are eligible for medical assistance under the State plan
 2 pursuant to paragraph (10)(A)(ii)".

3 (b) by adding after subparagraph (B) the following new
 4 subparagraph:

5 " (C) in the case of individuals under the age
 6 of 18 and individuals eligible for medical assist-
 7 ance under the State plan pursuant to paragraph
 8 (10)(A)(ii), no enrollment fee, premium, deductible,
 9 cost sharing, or similar charge with respect to any
 10 of the care and services listed in section
 11 1905(a)(4)(B) may be imposed under the plan;"

12 CONTINUATION OF ELIGIBILITY

13 SEC. 105. Section 1902(e) is amended—

14 (1) by inserting "(1)" after "(e)";

15 (2) in subsection (e)(1), as redesignated, by delet-
 16 ing ", while a member of such family is employed,";
 17 and

18 (3) by adding at the end thereof the following new
 19 paragraph:

20 "(2) Notwithstanding any other provision of this title,
 21 each State plan approved under this title must provide that
 22 any individual under the age of 18 (or, at State option, any
 23 individual under the age of 19, 20, or 21) who becomes ineli-
 24 gible, because of increased income from employment of him-
 25 self or his family, for medical assistance under the State plan

1 shall, nonetheless, remain eligible for all medical assistance
 2 provided under the State plan to such individuals until the
 3 end of the 4-calendar-month period beginning with the month
 4 following the month in which the individual became
 5 ineligible.”

6 **FEDERAL REIMBURSEMENT**

7 **SEC. 106. (a)** Notwithstanding any provision of section
 8 1903 of the Social Security Act, for the first calendar quarter
 9 beginning at least six months after enactment of this Act, and
 10 for each of the five succeeding quarters, the Federal medical
 11 assistance percentage for ambulatory care and services for
 12 children shall be the Federal medical assistance percentage
 13 as defined in section 1905(b) of that Act plus 4 percentage
 14 points.

15 **(b)** Section 1903(a) is amended by redesignating clause
 16 (7) as clause (8), and by adding after clause (6) the following
 17 new clause:

18 “(7) an amount equal to 75 per centum of the
 19 sums expended during such quarter for the costs to
 20 public agencies (or the private agencies pursuant to a
 21 contract with the State agency) of outreach in accord-
 22 ance with section 1913(a)(4).”.

23 **(c)** Section 1903(a)(1) is amended by deleting “subject
 24 to subsections (g) and (h)” and inserting instead “subject to
 25 subsections (g), (h), and (n)”.

1 (d) Section 1903 is amended by adding at the end there-
2 of the following new subsection:

3 “(n)(1) For the first calendar quarter beginning at least
4 24 months after enactment of the Child Health Assurance
5 Act of 1979, and for each succeeding quarter, the Federal
6 medical assistance percentage for ambulatory care and serv-
7 ices for children shall be adjusted as provided in paragraphs
8 (2) through (5) of this subsection.,

9 “(2) The Secretary shall promulgate, and may at appro-
10 priate intervals revise, regulations establishing a formula for
11 measuring the effectiveness of a State’s child health assur-
12 ance program, which formula shall take in account with re-
13 spect to children under the age of eighteen enrolled in the
14 State’s program under this title (other than children whose
15 eligibility is based on the cost of medical care to themselves
16 or their families)—

17 “(A) the percentage of such children who were
18 covered under an agreement with a continuing care
19 provider pursuant to section 1913(b)(2) and who re-
20 ceived, during the period under review, all necessary
21 care and services covered under such agreement; and

22 “(B) the percentage of such children not covered
23 by a continuing care agreement who

24 “(i) received, during the period under review,
25 a timely child health assessment, and received in

1 a timely manner after an assessment (as specified
2 by the Secretary in regulations) any necessary
3 medical care or treatment for conditions found
4 during an assessment, or

5 “(ii) were not due for assessment and did not
6 need treatment for conditions found during an as-
7 sessment.

8 The formula under this paragraph shall give greater weight
9 to the State’s performance as measured under clause (A) than
10 to its performance as measured under clause (B).

11 “(3) The Secretary shall publish, and may revise and
12 republish as appropriate, a formula for graduated adjustment
13 of States’ Federal medical assistance percentages (as defined
14 in section 1905(b)) with respect to the services specified in
15 paragraph (1), based on States’ performance with respect to
16 the standards established under paragraph (2). No State’s
17 Federal medical assistance percentage, as adjusted pursuant
18 to this subsection, shall be lower than 5 percentage points
19 below, or higher than 20 percentage points above (up to a
20 maximum of 90 per centum), its Federal medical assistance
21 percentage as defined in section 1905(b).

22 “(4) The Secretary shall evaluate at least biannually, on
23 a sample or other basis, each State’s performance with re-
24 spect to the standards established under paragraph (2), and
25 shall report his determination evaluating the State’s perform-

1 ance to the State not later than six months after the end of
2 the period reviewed.

3 “(5) The Secretary shall by regulation provide for a pro-
4 cedure whereby a State agency may demonstrate to the sat-
5 isfaction of the Secretary, with respect to any period, that it
6 has achieved a performance level which entitles it to a higher
7 Federal medical assistance percentage, pursuant to para-
8 graph (3), than the percentage determined by the Secretary
9 pursuant to paragraph (4).”.

10 EFFECTIVE DATE OF AID TO FAMILIES WITH DEPENDENT
11 CHILDREN PENALTY; REPEAL OF PENALTY; ADDITION
12 OF STATE PLAN REQUIREMENT

13 SEC. 107. (a) No reduction in the amount payable to
14 States pursuant to section 403(g) of the Act shall be made
15 with respect to any quarter beginning before the effective
16 date of final regulations pursuant to section 403(g) published
17 after January 1, 1979.

18 (b) Effective the first day of the first calendar quarter
19 beginning at least six months after enactment of this Act,
20 section 403(g) of the Social Security Act is repealed.

21 (c) Section 402(a) is amended by adding after paragraph
22 (16) the following new paragraph:

23 “(17) provide that the State agency shall inform
24 all families in the State receiving aid to families with
25 dependent children of the availability of child health as-

1 surance services under the plan of such State approved
2 under title XIX;”.

3 **TITLE II—MEDICAID ELIGIBILITY OF PREGNANT**
4 **WOMEN**

5 **MEDICAID ELIGIBILITY OF PREGNANT WOMEN**

6 **SEC. 201.** (a) Section 1902(a)(10)(A), as amended by
7 section 101 of this Act, is further amended by adding at the
8 end the following:

9 “(iii) for making medical assistance
10 available for care and services provided
11 during pregnancy and for 60 days following
12 the termination of pregnancy to any woman
13 whose resources (including the resources of
14 her family) meet the resources test of eligi-
15 bility for medical assistance under the State
16 plan approved under this title applicable to a
17 family with dependent children, and whose
18 income either (I) meets the income test of
19 eligibility for medical assistance under such
20 plan applicable to a family with dependent
21 children or (II) does not exceed 55 per
22 centum of the amount established for an indi-
23 vidual or for a family of that size, as appro-
24 priate, by the income poverty guidelines for
25 the nonfarm population of the United States

1 as prescribed by the Office of Management
 2 and Budget (and adjusted annually) pursuant
 3 to section 625 of the Economic Opportunity
 4 Act of 1964;”

5 (b) Section 1905(a) is amended—

6 (A) by striking out “or” at the end of clause (vi);

7 (B) by inserting “or” at the end of clause (vii);

8 (C) by inserting after and below clause (vii) the
 9 following new clause:

10 “(viii) women during pregnancy and
 11 during the 60 days following the termination
 12 of pregnancy,”.

13 REQUIRED COVERAGE FOR PREGNANT WOMEN

14 SEC. 202. Section 1902(a)(13)(B) is amended to read as
 15 follows:

16 “(B) in the case of any individual described
 17 in paragraph (10)(A), for inclusion of at least the
 18 care and services listed in clauses (1) through (5)
 19 of section 1905(a), and”.

20 CONTINUATION OF ELIGIBILITY

21 SEC. 203. Section 1902(e)(1), as amended by section
 22 105 of this Act, is further amended by adding at the end
 23 thereof the following new paragraph:

24 “(3) Notwithstanding any other provision of this title,
 25 each State plan approved under this title must provide that

1 any pregnant woman who is eligible for, has applied for, and
 2 has received medical assistance under this title and who be-
 3 comes ineligible for such assistance because of increased
 4 income from employment of herself or her family, shall, none-
 5 theless, remain eligible for all such medical assistance pro-
 6 vided under the State plan until the end of the 60-day period
 7 beginning on the date of the termination of her pregnancy.”.

8 TITLE III—EFFECTIVE DATES; REGULATIONS

9 EFFECTIVE DATES; REGULATIONS

10 SEC. 301. (a)(1) Except as otherwise expressly pro-
 11 vided, the amendments made by this Act shall apply to medi-
 12 cal assistance provided, under a State plan approved under
 13 title XIX of the Social Security Act, on and after the first
 14 day of the first calendar quarter beginning at least six months
 15 after enactment of this Act.

16 (2) Where the Secretary determines that State legisla-
 17 tion is necessary to permit amendment of the State plan
 18 under title XIX of the Social Security Act to meet the addi-
 19 tional requirements imposed by the amendments made by this
 20 Act, he shall not find a failure to comply with the require-
 21 ments of such title solely on the basis of such State’s failure
 22 to meet these additional requirements before the first day of
 23 the first calendar quarter beginning after the close of the first
 24 regular session of the State legislature that begins after the
 25 date of the enactment of this Act.

- 1 (b) The Secretary shall issue the regulations required by
- 2 this Act within six months after the date of enactment of this
- 3 Act.



DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

JUN 10 1979

The Honorable Harley O. Staggers
Chairman, Committee on Interstate
and Foreign Commerce
House of Representatives
Washington, D.C. 20515

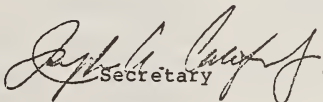
Dear Mr. Chairman:

This is in response to your request for a report on H.R. 4053,
the "Child Health Assurance Act of 1979."

We transmitted the bill to the Congress, on behalf of the
Administration, on May 10, 1979, with accompanying explan-
atory materials, and urged that it be promptly and favorable
considered.

We are advised by the Office of Management and Budget that
the bill's enactment would be in accord with the program
of the President.

Sincerely,


Secretary



EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

(U)
(favourable)

JUL 13 1979

Honorable Harley O. Staggers
Chairman, Committee on Interstate
and Foreign Commerce
House of Representatives
Washington, D. C. 20515

Dear Mr. Chairman:

This is in response to your request of June 15, 1979 for the views of this Office on H.R. 4053, a bill "To strengthen and improve medicaid services to low-income children and pregnant women, and for other purposes."

H.R. 4053 is identical to draft legislation submitted by the Secretary of Health, Education, and Welfare on May 10, 1979. The bill would authorize HEW to carry out a new expanded program of health screening and treatment for children of poor families by replacing the current Medicaid Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT) with a new Child Health Assurance Program (CHAP).

We concur with the views expressed by the Secretary of Health, Education, and Welfare in his transmittal letter. Accordingly, we recommend that the Committee give favorable consideration to the bill. Enactment of H.R. 4053 would be in accord with the program of the President.

Sincerely,

Naomi R. Sweeney

Naomi R. Sweeney
Acting Assistant Director
for Legislative Reference

Mr. WAXMAN. Ms. Davis.

STATEMENT OF KAREN DAVIS, PH. D., DEPUTY ASSISTANT SECRETARY, PLANNING AND EVALUATION/HEALTH, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE, ACCOMPANIED BY RICHARD HEIM, DIRECTOR, MEDICAID BUREAU, HEALTH CARE FINANCING ADMINISTRATION, PUBLIC HEALTH SERVICE

Dr. DAVIS. I have with me today Richard Heim, Director of the Medicaid Bureau of the Health Care Financing Administration. I am pleased to have the opportunity to appear before you today in support of H.R. 4053, the administration's child health assurance program. I know that you are strongly committed to the goals of this legislation: to providing adequate health services to our Nation's children and pregnant women. I know that you share a special concern for low-income children and pregnant women, for whom ongoing preventive health care is too often a luxury. Yet, we know that timely and appropriate preventive care can mean the difference between a life of suffering and disability and a life in which every child has the opportunity to reach her or his fullest potential.

Mr. Chairman, CHAP represents an immediate step which should be taken to overcome barriers that limit access to health services for low-income children and pregnant women. Passage of the child health assurance program offers a unique opportunity to address one of our Nation's most pressing health care needs—that of insuring that no low-income child or pregnant woman, as defined by our national income standard, is denied coverage of basic health care services.

As you know, the Interstate and Foreign Commerce Committee reported out CHAP legislation during the last Congress. Unfortunately, time ran out and CHAP never reached the House floor. Mr. Chairman, I strongly hope that the House will seize the initiative to act quickly and complete the unfinished task begun by the committee last year.

I would like to point out that in restructuring our CHAP proposal, we built upon many of the excellent suggestions and amendments proposed by members of this committee. For example:

Our new proposal contains a minimum income standard similar to that in H.R. 13611.

Our bill also includes the committee's decision to extend dental benefits to all medicaid children.

Our current legislation places a stronger emphasis on the importance of outreach by adopting this committee's amendment to raise the Federal matching rate for outreach services by private and public groups.

Secretary Califano summarized our knowledge of child health problems during your recent child health oversight hearings. Many of these same statistics were also noted by the chairman in his opening statement and in the testimony of others appearing before this committee.

I will not reiterate these figures but I will stress an important message conveyed by these statistics.

Although we have made great strides in improving the health of children, millions of children still fail to receive adequate health care services. Nearly 6 million children under the age of 17 are estimated to have no regular source of health care; 10 percent of children 6 through 16 have never been to a dentist.

Many of those who do receive care, receive only episodic, fragmented services in response to an immediate crisis; they seldom receive the full range of preventive and primary care services needed for proper growth and development.

This burden falls most heavily upon the poor. Poor children are more likely to be in poor health, to develop communicable diseases, to have functional disabilities, and to die within the first year of life as children in families with higher incomes.

The Department of Health, Education, and Welfare administers a variety of programs aimed at improving health care for children. In fact, Secretary Califano outlined for you a number of our major programs serving children during his recent testimony before this committee. These include the title V maternal and child health program, the community health center program, and the medicaid program, and others.

The medicaid program, in particular, has been responsible for making health services available and accessible, and improving health status, for many poor children. Millions of low-income children have received inpatient hospital services, outpatient services, and physician visits under medicaid alone.

As the Secretary noted, we are committed to improving the coordination and upgrading the quality of medicaid and all other programs serving children. In fact Secretary Califano has initiated a number of important administrative actions within HEW to improve coordination and maximize the effectiveness of existing child health programs.

Yet despite the existing child health programs and services, our health care system for children does not go far enough. These programs alone are not sufficient to respond adequately to the needs of poor women and children. There are two basic reasons for this shortcoming. Current programs fail to cover many low-income children and pregnant women; and existing programs fail to place enough emphasis on preventive care.

The medicaid program is essentially a payment program. It assures eligible persons that when they need health care, the bill will be paid. However, the Congress recognized the need to do more for children than insure financial access. The early periodic screening diagnosis and treatment program (EPSDT) was enacted to specifically meet the health care needs of children, including health outreach and health status monitoring.

Under EPSDT the States are required to make a positive effort to inform parents that their children are eligible for this service; to offer the service to them at appropriate intervals to regularly assess the health status of eligible children and diagnose particular problems; and to assure needed and requested followup treatment is provided.

Yet, medicaid/EPSDT has serious shortcomings: medicaid fails to cover many low-income children and pregnant women. Although 11 million children are eligible for medicaid, another 7 million chil-

dren live in families with incomes below the Federal poverty level but are not covered. Some of them are ineligible because they live in two-parent families; others because their family income is slightly above restrictive State welfare standards.

Roughly 600,000 women with incomes below the poverty level may become pregnant and need prenatal and delivery services each year. Of these, 250,000 are not covered by medicaid. Some are ineligible because they live in two-parent families or are pregnant with a first child, and do not qualify for cash assistance on which medicaid is based. Others have incomes just above State welfare standards.

Some essential child health services are severely restricted by States. Current law requires States to provide dental, hearing, and vision services only to children screened under EPSDT. Other children may be denied these vital services. Moreover, mental health services are often so limited that only minimal levels are provided. Inpatient and outpatient medical services may be limited as to amount, duration, or scope; copayments may be imposed for essential prescription drugs.

Largely due to lack of incentives to States, EPSDT fails to reach most eligible children. Only 30 percent of all medicaid eligible children have been reached and assessed for health problems. The present program poses financial burdens for States without providing appropriate incentives. In addition, penalties have been rigid and difficult to enforce.

EPSDT also fails to insure followup treatment and ongoing care for those who are reached. Almost 30 percent of those screened and found to need treatment do not receive it. Others receive episodic and fragmented followup which may even duplicate the screening they have already received.

The most effective way to insure followup treatment is for the child to be in a comprehensive care situation in the first place. But screening has not usually been an integrated part of ongoing care. Instead, some States further fragment the system by using the welfare system for intake, the health department for screening, and the private sector only for treatment referrals.

It is not surprising that in such a system, provider participation is low. Participation is further discouraged by minimal reimbursement rates and lack of timely claims processing.

Mr. MAGUIRE [presiding]. We do have a vote on the floor. I wonder if we could break the testimony at this point when you are just about to tell us what the solution is.

Dr. DAVIS. Thank you.

Mr. MAGUIRE. Excuse me, and we will go over to the floor for a vote.

[Brief recess.]

Mr. MAGUIRE. We will resume the hearing at this time.

Madam Secretary, would you continue?

Dr. DAVIS. As you indicated, I would like to summarize some of the ways in which our CHAP proposal addresses many of the problems that exist in the current medicaid program.

First, CHAP establishes a minimum income standard at 55 percent of the Federal poverty level without family restrictions. CHAP mandates coverage for all children under 18 in families with in-

comes under the 55-percent minimum, or the State standard, whichever is higher. This includes children in two-parent families. It is a significant step, adding 2 million new children to the eligible pool.

Coverage is also mandated for pregnant women with incomes under the 55-percent minimum, or the State standard, if higher. This includes women in two-parent families and those who are pregnant for the first time. It should make 100,000 additional women eligible for prenatal, delivery, and postpartum services each year.

CHAP also encourages followup care through an eligibility grace period. Children who lose financial eligibility can continue on medicaid for 4 months. Pregnant women retain their eligibility for 2 months after the termination of pregnancy.

Second, CHAP mandates additional services, not just for screened children, but for all medicaid children. This improves administration and ends the artificial distinction between screened and unscreened children. CHAP requires that States cover the following services for all medicaid children in addition to normal State plan benefits: routine dental services, vision and hearing services, prescription drugs and insulin, immunization, and ambulatory mental health services.

In addition, CHAP mandates uniform health assessments with appropriate requirements for specific age groups. States cannot impose copayments on these mandatory services for children. CHAP overrides States' limitations on the amount, duration, and scope of most mandatory services including inpatient hospitalization.

Third, an important new feature of CHAP is the way it provides incentives to States. Initially, all States will receive a 4-percentage-point increase in their Federal matching rate for ambulatory services to medicaid children. This will cover startup costs early in the program.

After the startup period, a State can receive up to 20 percentage points added to its current Federal matching rate, to a maximum of 90 percent for ambulatory services to medicaid children. The amount added will depend on the proportion of eligible children either under continuing care, or receiving timely assessments and treatment. More weight will be given to children under the care of continuing care providers in the calculation.

Instead of a separate penalty, a State may lose up to 5 points in its Federal matching rate for ambulatory services to medicaid children, if the above proportion falls below a minimum standard.

Fourth, CHAP provides incentives to continuing care providers. A new category of providers will be established, who agree in writing to take responsibility for assessment and ongoing care for specific medicaid children. These providers must be available on a continuing basis as a primary medical source. They must agree to maintain records and provide medical management.

In return, CHAP gives the Secretary authority to specify special incentives for these providers, including higher reimbursement rates, bonuses for case management, or capitation arrangements for ambulatory care.

As you know, Mr. Chairman, this committee will also consider CHAP proposals introduced by you and Mr. Waxman, and Dr. Carter, in addition to the administration's bill. Each of these proposals seeks to expand the number of medicaid eligibles, enlarge the range of available benefits, and provide financial incentives for States to reach and treat more children.

All of the proposals use a national income standard to bring additional poor children and pregnant women into the medicaid program. Our bill extends eligibility to those with incomes under 55 percent of the poverty level, or an estimated \$4,100 for a family of four in 1980 dollars.

Dr. Carter's proposal would add children and pregnant women in families below a \$4,200 floor. The CHAP bill introduced jointly by Mr. Waxman and Mr. Maguire would include a more generous criteria, all those in families below 66 percent of the poverty level, or \$5,000. As you can see, the differences here are among actual levels, not principle.

The three bills do contain more basic conceptual difference in the way benefits are expanded and in providing incentives to States. Unlike other proposals, our CHAP bill provides a broader range of benefits to all medicaid children. Both Dr. Carter's proposal and that of you and Mr. Waxman expand medical benefits only for assessed children.

We choose to broaden coverage for all medicaid children, regardless of assessment status so that no child would be denied essential care because she or he failed to receive a health assessment. The one area in which all three bills have chosen to expand benefits to all medicaid children is dental care.

Other CHAP bills include a fixed higher match based on services to assessed, rather than all medicaid children, and a separate penalty and bonus. After careful consideration, we have concluded that a performance-based match is easier to administer because it does not require distinguishing between assessed and nonassessed children in determining the higher match. Also, it requires States to earn the higher match and allows differences in performance to be reflected in the graduated Federal matching rate.

Finally, our legislation seeks to address directly the problems of fragmented care and low provider participation. The use of continuing care providers moves CHAP away from the EPSDT model which tends to fragment screening, diagnosis, treatment, and followup. The provision of ongoing preventive and primary care services by a single provider will help to assure that poor children enjoy the same ongoing preventive and primary care services received by more affluent children. The direct financial incentives should encourage providers to enter into continuing care relationships.

I would like to call your particular attention to the way in which we have expanded benefits for all children and structured incentives to eliminate fragmented care. These new features are the result of extensive consultation with States, providers, and consumers, and we believe they represent a feasible and workable approach to some very difficult problems.

Mr. Chairman, I urge this committee to consider and pass the proposal as quickly as possible. We are confident that the improve-

ments we are proposing will give the Federal Government, the States, consumers, and providers of health care significant opportunity to reach out and serve more needy children and pregnant women.

Thank you.

Mr. MAGUIRE. Thank you.

I want to refer to my opening statement. It simply says that unfortunately Congress adjourned before we were able to pass a CHAP bill in the last session.

The bills that we have before us now, including the one that Secretary Davis has just presented to us, clearly show the continuing determination of members of the committee and of the administration to establish a viable program that will be truly responsive to the multifaceted, continuing needs of low-income children and adolescents and pregnant women. I'm encouraged by the keen, widespread bipartisan support CHAP has received thus far. I know all of us are looking forward to hearing testimony on the various bills, as we will in this and subsequent hearings.

The testimony should and I am sure will guide us toward the most effective CHAP legislation which would be designed to maximize the normal health and development of our Nation's children.

We are all familiar with the quotation that the child is the father of the man, and surely it is imperative that we focus on ways in which we can deliver appropriate services to all children who are growing up in the early stages of their lives.

Guarding physical and mental health during formative years will help to insure a more positive environment for growth and development, and this, in turn will lay the groundwork for a healthier adult population for people of all socioeconomic levels. That is what this effort is all about and I certainly welcome your very fine statement here today.

Mr. Gramm, proceed with the questioning.

Mr. GRAMM. Madam Secretary, as it would be covered by this CHAP program, we talked about vision as being an area of supervision and treatment.

Do you have specifications in the CHAP bill as to who will provide this care, ophthalmologists or optometrists?

Dr. DAVIS. The bill does mandate, as part of the assessment, that the State would provide vision screening and it does mandate that the State provide vision services. As with all services in the Medicaid plan, the State government basically has the responsibility for certifying eligible providers.

Mr. GRAMM. So the State can certify ophthalmologists or optometrists, or a combination of both, or they could divide it so far as eye health is concerned. They could choose some mix. The State could do that and the bill does not exclude that, is that correct?

Dr. DAVIS. That is right.

Mr. GRAMM. The logic for mandating a zero coinsurance payment, as I listened to your testimony, is basically to assure that no child is precluded from entering into the market.

Dr. DAVIS. That is true. We are talking about individuals with incomes below 55 percent of the poverty level, for the most part, which is \$4,100 for a family of four.

So for that group of patients, we do not think there should be a financial deterrent to care. There are frequently other deterrents such as the costs of time and travel when people have to miss work to take their children in to get assessments.

Mr. GRAMM. There are very few people with a family income of \$4,500 who are working unless they are violating the minimum wage law.

Dr. DAVIS. That has been known to happen but some do work part-time or have other obligations.

Mr. GRAMM. My concern, and I should express it here is that I'm going to support the CHAP program but my concern is a concern that I have about all medical programs, and that is how do we assure that people get care without also setting up a system which induces people to waste those services or overuse them?

I am not sure I know the answer to that, but I have a concern about all of our health programs that are paid for by third-party payers, whether they be the Government or the private sector, if they have near zero coinsurance payment and if they have no minimums or no deductibles. Then the only cost to an individual consuming the services represents a time cost and then the basic decision comes down to the value of their time in being a deterrent from overusage.

I would simply like to express the concern and I would like to get your views of it. The advantage obviously of no coinsurance payment is we insure that any child has access. Now, I think there is no dispute on this committee about giving medical treatment to children.

The question I have is, are you not concerned that this may induce a waste of medical resources?

Dr. DAVIS. I am not concerned about this issue. I think our major problem in the area of health care for children is that children have typically underutilized preventive services and have not received comprehensive physical examinations on a regular basis. Often we have not found conditions early enough to prevent their spread; this had lead to more acute conditions or even chronic conditions. For example, failure to treat ear infections can lead to loss of hearing over a period of time.

Our experience with the medicaid program where individuals do not pay cost-sharing, or any portion of the bill, is that low-income children who are covered by medicaid have begun to receive services for acute care at least the same rate as middle-income children.

You may argue middle-income children go too frequently or that there is some abuse, but we have not found overuse of physician services under the medicaid program where we have no cost-sharing when compared with the utilization patterns of higher income groups.

So overutilization it has not been our experience under the medicaid program.

Mr. GRAMM. That is an encouraging statistic, and I hope that the Department will continue to monitor that. What we want to do is hit a happy balance. These resources are expensive to provide and they are obviously valuable, which is why we want to provide them, but we in a sense don't want to maximize them, and we

want to optimize them from the point of view of getting their usage up to the point where the benefit people get equals the cost to society.

The whole third-party payer problem is that the person getting benefits is not the person who is paying, so that it is hard to keep these things in balance, and I am encouraged that you have looked at these figures in designing this program.

Thank you, Mr. Chairman.

Mr. MAGUIRE. Thank you.

Dr. Davis, in the recently published new penalty regulation direct referral to a dentist is part of the mandated screening package, and yet the administration's CHAP proposal does not specifically include dental referral as a responsibility of providers.

Is that because the Department assumes that the recently published screening package, including the direct referral to a dentist, will be in the assessment protocol under CHAP, or what is going to happen?

Dr. DAVIS. As I indicated in my testimony, the CHAP proposal would mandate coverage of dental services. It also requires that the States inform all individuals of the availability of dental services.

States, for example, would be expected to provide medicaid eligible-families with a list of dentists participating in the program. It is through these types of efforts to inform families make this benefit available and to make it known to patients that it is possible to see a dentist that we do think that the dental care is important, and that is why we have mandated this coverage.

Mr. MAGUIRE. Now, on page 8, you talk about provisions in CHAP which override States limitations on the duration and scope of most mandatory services, but in fact, as I understand it, I guess the "most" that you use there is the controlling word because under your proposal the State can limit dental in amount, scope, and duration.

Is that not correct?

Dr. DAVIS. That is correct, but even under the current medicaid program, if that were excessive, general authority is broad enough to allow the Secretary to point out to the State that it really did not leave a minimum enough standard to make sure that the service was available.

Mr. MAGUIRE. There is a minimum standard provided for with respect to mental health, but I was not aware there was a minimum here.

Dr. DAVIS. It is part of the general medicaid authority on what is an acceptable medicaid plan.

But you are correct, this is the only service about which we do not explicitly say there can be no restrictions on amount, duration, or scope except for mental services which we address very specifically by specifying the conditions under which they are set.

Mr. MAGUIRE. Why not address dental specifically as well?

Dr. DAVIS. I think part of the thinking here is that we have not had as much experience with that, and we are going to leave a little bit more discretion to the States to gain experience with it, but it is one area where we have not——

Mr. MAGUIRE. Or perhaps save some money by not having the minimum criteria too explicit.

Dr. DAVIS. Well, we wouldn't put it in the package at all if we weren't concerned about the need for dental care as a benefit and felt it was important that children get it.

Mr. MAGUIRE. What would you envisage as the minimum criteria for mental health services? Would you have anything to tell us on that?

Dr. DAVIS. Again, this is an area which is fairly new and one we want to look at, but some of the types of things we have looked at indicate particularly that getting entry into the medical health system is very important. Thus, for the first few visits, we would not like to see deterrents to care.

At some point, after a few visits, it might be appropriate to have some provision, for example, to look at the need for continuing mental health care through some kind of a peer review system. We would see that type of mechanism as being acceptable.

Mr. MAGUIRE. Historically, one of the weakest parts of the EPSDT program has been followup, something like 40 percent, I guess your statement says 30 percent of the problems identified as needing followup care go unattended.

Yet in your bill, followup services are reimbursed at current rates. Now, if we want to make sure that children get to the care they need, doesn't it make sense to provide a higher Federal matching rate for followup services?

Dr. DAVIS. Initially, in the first 18 months of the program, we would increase the Federal match on all ambulatory services provided to children. We do not increase the match on the hospital institutional services, but we would increase the match by a uniform amount in the first 18 months, and then implement the variable match depending upon performance.

So, yes, while we don't do it on the hospital side, we do provide a higher match on ambulatory services, followup care.

Mr. MAGUIRE. Let me just call on counsel.

Ms. NELSON.

Let me ask you, is the increased match for services under the medicaid program? Followup services, if performed by a physician, would be included in his service cost. If performed by a community organization the costs of followup would be matched as an administrative cost under this program.

Dr. DAVIS. It would be an administrative cost.

Ms. NELSON. And the increase in that is a little different, is it not?

Dr. DAVIS. That is right.

Mr. MAGUIRE. It looks as if under your bill, the outreach is going to get a higher level of encouragement than the followup services. However there will be some problems with outreach in using the performance standards, since you are going to be measuring the number of people who are being served against the total number enrolled, with the result that people's performance is going to be to some extent dependent on how few they actually enroll.

There seemed to me to be some structural problems here that perhaps you could comment on. On the one hand, you seem to be giving more reimbursement for getting people into the program and for followup, and then on the other hand, when you measure performance of how are people doing, in this State or that State, it

seems to push the other way. That is, there seems at that point to be incentive on getting fewer people into the program in order to have a better track record of serving them.

Do you follow the question? I am not sure I am entirely right in stating it, but I think that that is right.

Dr. DAVIS. In terms of increasing the match, it is the ratio of the children assessed and treated plus those in continuing care, divided by the total number of children eligible for medicaid. We do not feel that this would be a serious disincentive to enroll. Even in other bills before the committee, which have a performance bonus, they would tie that to performance standards such as the proportion of eligible children who were assessed, so I think you have the same kind of problem whichever approach you take.

But we are mandating that States cover all children up to 55 percent of the poverty level. We feel there are not going to be serious problems in terms of disincentives to enroll. We feel that this is going beyond just tying a higher match to assessed children, that the performance standard would be on measured the basis of children assessed and treated and under continuing care, so there would be adequate followup.

If a child were assessed but were not followed up with adequate treatment, that child would not be considered assessed and treated, and it would not meet the performance standard.

Mr. MAGUIRE. But your performance is also going to be dependent on the number of eligibles that you locate in the first place, with the result that you will appear to have a higher performance standard the more eligible children you fail to find.

Dr. DAVIS. We feel that we are addressing the problem of not finding all children who are eligible and getting them assessed by putting more emphasis upon outreach. We do increase the match to 75 percent for both public and private agencies doing outreach and we think that will lead to virtually full enrollment. We currently estimate under the AFDC program that about 90 percent of those eligible do get enrolled. I think with the visibility that we plan to give to this program, and through the support of the groups that are interested in promoting this, that in fact those children are going to find out about the program and get signed up.

Also, it is to the advantage of physicians and hospitals who come in contact with these children to advise their families of the availability of this program; they will be interested in getting children signed up.

I might also state that there are a number of ways in which we do stress followup. We think that the real key to getting adequate followup is to have continuing care providers in this program, and we have gone to some extent to encourage physicians, health centers and other organized settings to become continuing care providers.

There may be bonuses to such continuing care providers for case management so that apart from treatment services, general follow-up services will be provided; For example, finding out whether the child took the prescription drug that was ordered, came back for a second visit, or went to a specialist. We could give bonuses to the continuing providers for those kinds of followup services; for that type of case management activity.

So that outreach and followup are both included.

Mr. MAGUIRE. Before we get to the case management, and I think all of that is very good, but I wonder if you could tell us more about the specific strategies that would be employed to assure that those who are eligible would be enrolled and in turn seen by CHAP or other continuing care providers here.

You increase eligibility, but you do not, for example, spell out the additional outreach approaches which we do in our bill. With local community-based organizations, for example, encouraging them by reimbursing them at 90 percent levels, requiring that States devote some more resources to the outreach effort, and so on. What strategies would you envision under your legislation?

Dr. DAVIS. First of all, I stress that the national publicity about the availability of eligibility for new groups would be very significant in attracting families into this program.

Mr. MAGUIRE. National publicity would be?

Dr. DAVIS. I think that one step is to make it well known that a new program is available and to advise hospitals and physicians to make this known.

For example, you can publicize CHAP through the food stamp program, so that families can find out about it. I would not under-rate those kinds of informational publicity activities.

I think that they are very important to this effort.

Second, we plan to monitor the number of potential eligibles. We do have State-by-State estimates now of the expected number of new children who would be eligible under this program. We can go in State-by-State and monitor what their experience has been: Have they actually increased the number of eligibles in that State to the extent we envision under our current estimates?

Obviously, advocacy groups have the right to take the issue to court if they feel it is not being well implemented and that children we are not being reached. I think that the mere fact that we are really putting a lot more in through extra incentives and making this program much more attractive to physicians, community health centers, and other kinds of primary providers will mean that these organizations will join with us in trying to find individuals who are eligible.

We also, as I indicated, are increasing the match to 75 percent to apply to both private agencies and public outreach agencies. I think that will be very important in getting the word out.

Mr. MAGUIRE. OK. Well, that is all very helpful, but I think the fact of the matter is that there are a lot of people who are not necessarily going to be reached by "publicity," or even providers who may need an additional encouragement to provide.

A certain number of people are going to be best reached through peer contacts in their communities, using organizations that are already there and already working and have the kinds of relationships with the families and parents around other kinds of activities that are going to give the program credibility and status in the community.

What are the arguments against doing that, the kind of thing that we try to do in the bill with respect to community-based outreach?

Dr. DAVIS. I think one major difference in your bill is that you would go to a 90-percent match on private outreach agencies and a 75-percent match would remain for public agency outreach. We did not see the reason for discriminating against the public agencies where they were doing a good job; that is one small source of concern.

Mr. MAGUIRE. But the fact is they have not been doing a good job because we have EPSDT with these very low figures of effectiveness.

Dr. DAVIS. I think that is true, as an average statement. There certainly are States that have done a good job and have reached a fairly high proportion of eligible children.

Mr. MAGUIRE. Well, would you support a legislative requirement that community organizations be used for outreach, or would you oppose that, or be neutral with respect to it?

Dr. DAVIS. We have been very impressed by the performance of the community organizations. I do not know whether you want to totally tie the States' hands so that if there were organization which were not effective, the State would have to go ahead and use them and pay those groups to do outreach. I think that would be our only concern.

Mr. MAGUIRE. Well, after 3 or 4 years in the program, suppose we have a smaller number of children enrolled in other States with comparable sized low-income populations. Would you then take additional steps on outreach of the sort we are discussing, or would you lower the Federal matching rate for the State if the enrollment rate was low, or what would you do?

Dr. DAVIS. In terms of reaching eligible children, obviously the performance standard would actually give them up to a 5 percentage point penalty were they not to assess or get into continuing care a large proportion of eligible children.

So that that provision is important.

Mr. MAGUIRE. Let me complete this set of questions for now and then I will call on my colleague here. What would you expect the performance standard to be for a State to receive the full extent of the 20 percent bonus? Would you expect 50 percent of eligible children to be assessed in 2 years, 75 percent within 4 years, or what standards would you expect to use?

Dr. DAVIS. As the legislation indicates, we would go up to a maximum of 20 percentage points and would like some flexibility to gain some experience with this before nailing it down.

At present, based upon information we have now, we would plan to say that if, perhaps 20 percent of all eligible children were assessed and treated, or in continuing care arrangements, there would basically be no additional match. That would be the minimum standard, and if you were lower than this standard would be subject to a 5 percentage point penalty.

Basically, for every 4 percentage points that the State improves that ratio, that it improves the proportion of children who are either in continuing care or treated, the State would get a 1 percentage point increase in its match. If done that way, basically it would require 100 percent of all children to be either under continuing care arrangements or assessed and treated to get the full additional 20 percentage points.

Now, one small change is that we would like to weight a little more heavily those children who get into continuing care arrangements, perhaps, count those children at 1.2 points. Thus if you had the bulk of your children in continuing care arrangements, even if only 80 percent were enrolled, a State might get the full 20 percentage points increase in its match.

Mr. MAGUIRE. Does it make sense to write these formal standards into the law?

Dr. DAVIS. I think, in any new program, it is always good to have some flexibility. We are working from data that are not perfect, and we are trying to improve that data to get a better understanding of how it varies by State currently as to the number of children who are in continuing care arrangements.

I think it would be wise to leave some flexibility to alter that schedule as we got better data.

Mr. MAGUIRE. Are these percentages that you have given us, do they apply equally to all States? Would you take into account where a State started and measured its relative progress?

Dr. DAVIS. That is right. So if a State is very high now, at the beginning of this program, under this performance match, they would receive a much higher increase.

Mr. MAGUIRE. How are you going to verify statement forms, use sampling techniques, or what?

Dr. DAVIS. We do plan to use a sampling system so that we would not require reports on 100 percent of all children.

Mr. MAGUIRE. Will the States draw the samples under your instructions, or will you do it, or what?

Dr. DAVIS. I would like to ask Richard Heim, who is here representing Mr. Shaffer to speak to that.

Mr. HEIM. The approach we would use in sampling would be that the regional offices of the Health Care Financing Administration would go into the State and actually draw the sample and would verify the children in the sample.

It would be a random sample, either under continuing care and therefore under a provider who would agree to deliver all of the services, preventive as well as acute and episodic services for that particular child, or that that individual child was not scheduled for an assessment that year, that the period has been reached, would be up to date, and for those not in that schedule they would actually go out and get claims or what samples or get the actual claims forms that had been provided for that child for that period of time to see whether the required services had been performed or not.

It would be done first of all to take the universe, take a random sample and then remove from the sample those who were under continuing care, those who were not scheduled for assessment that year, and the balance would go on and actually review what services had been performed for that child in the sampling period.

Mr. MAGUIRE. The question of whether or not you are accurate, and your information must be very accurate, is very important because you are talking about dollars and variable levels of reimbursement, and so on.

Now, are you confident you are going to get accuracy through this period?

Mr. HEIM. It will be a random sample, and scientifically drawn and scientifically valid. We are using the same type of approach in other programs Mr. Chairman, and we are confident that if carefully done, that this would be valid.

However, there is an escape hatch for a State that channels the findings, that in the proposed legislation a State which disputes the findings can come in and demonstrate to the Secretary that the findings are inaccurate and we can produce evidence to that fact.

Mr. MAGUIRE. Mr. Dannemeyer, do you have any questions?

Mr. DANNEMEYER. I am asking these questions on behalf of Dr. Carter, who wanted to be here this morning, but I am advised he is unable to be with us.

Please explain how the administration arrived at some of the eligible requirements in the proposal. Why was 55 percent of the poverty level picked as the minimum income standard, and why is there only a 4-month grace period, and why have you excluded hard-to-place adopted children and those poor children living in State-operated institutions?

Dr. DAVIS. The eligibility standards would require that all children and pregnant women below 55 percent of the Federal poverty level be covered. In some ways, any given poverty level or percent of the poverty level is somewhat arbitrary and one has to weigh the budgetary consequences of going to higher standards.

After looking at a number of alternatives, we decided on this level. It is the income standard roughly equivalent to that used in the Commerce Committee bill last year, and also roughly equivalent to Dr. Carter's income standard.

On the 4-month grace period, the other proposals before the committee have 6-month grace periods for assessed children. Our bill would provide a 4-month grace period for all medicaid children. Currently, there is a 4-month grace period for AFDC children, but no grace period mandated for medically needy families or for so-called Ribicoff children, that is, children currently covered in certain States whose families are not on the AFDC program.

So, first of all, for administrative ease, if we make it a 4-month grace period in this bill, it will correspond with current treatment in the AFDC program. You will not have children on for a longer period of time than other members of the family. Second, we think that 4 months is usually adequate to receive treatment for any conditions that might be found in assessment. One of the problems with the current program is that a child could be assessed and then become ineligible for medicaid before the provider could provide treatment for the conditions found in the assessment. For this reason, we would like to extend the grace period for 4 months to make sure that the child is treated for all conditions found in the assessment and we feel 4 months is adequate.

We did not include, in this bill, coverage of children in State-operated institutions. We feel that this is largely fiscal relief to the States. They are currently providing medical care for the children in those institutions, and that there was less of priority to substitute money to pick up their care.

Mr. DANNEMEYER. Thank you.

Why does not the administration include provisions to address the problem of children of migrant workers?

Dr. DAVIS. The coverage of migrants is of strong interest to the administration. It is not included in this specific bill because we had originally thought it would be fairly easy to develop regulations that would insure that migrant children were covered under current statutory authority.

The President has even included \$9 million in his budget to assure that these migrant children would be covered in the medic-aid program. However, as we tried to develop regulations in this area, it required more complex changes than we had initially anticipated. We support the concept and this might be an area that the committee would be interested in pursuing.

Mr. MAGUIRE. If the gentleman would yield, just to expand the very excellent question that he has asked you to comment on, I would ask you to comment on juveniles in institutions and adopted children, who are otherwise categorized, that are specified in some of the other bills which the committee has before it, and you have not specifically addressed.

Dr. DAVIS. The hard-to-adopt children are included in the administration's child welfare bill. We do support covering these children under the child welfare bill, but we have not included it as a separate item in this legislation.

As to juveniles who are in State institutions, we did not include that provision in part because we felt that the States are already picking up that medical care at 100 percent cost. Thus, rather than using Federal money to insure that more children got services, we would just be providing fiscal relief to those States for care that they are currently providing.

On the migrant children, we do think that it is very important that they be covered.

Mr. DANNEMEYER. Why does not the administration of the bill include provisions to insure coordination of the various child health programs, particularly titles V and XIX?

Dr. DAVIS. The administration is very concerned about the coordination of all of its child-related programs. The Secretary testified before the committee in your oversight hearings as to a number of steps that the Department is taking internally to coordinate these programs.

We do not believe that there is necessarily statutory authority and we are at this point moving to improve the coordination of these programs administratively.

For example, one of the things we are looking at is the reimbursement under our financing programs such as medicare and medicaid for title V maternal and child health centers and community health centers and trying to work on much of that coordination administratively.

Mr. DANNEMEYER. The administration bill authorizes the Secretary to use discretion in limiting the amount, scope, and duration of mental health services. What provisions are in the bill that will assure these limitations are consistent with quality standards of care?

Dr. DAVIS. In the case of mental health services, if the State was to set limits on the amount, duration, and scope of services that were not adequate, there is provision for the Secretary to set basic

minimum standards. The State would have to meet, at least, that minimum standard.

So in the case of mental health services, there is authority for the Secretary to set up higher standards if necessary to bring States up to that standard.

Mr. DANNEMEYER. In the past, the Department has failed to carry out vigorously the provisions of EPSDT. What are the Department's plans to strengthen the central and regional offices to implement CHAP?

How many professional staff presently work full time on EPSDT in the central office or regional offices? How many more staff would be necessary to carry out the program?

Dr. DAVIS. I would like to ask Richard Heim, who is the head of the medicaid bureau, to respond to that.

Mr. HEIM. Presently, we have possibly 11 central office staff devoted to monitoring the new penalty which will be going into effect in October. Also, there are some 22 staff for monitoring purposes and the total staff for monitoring child health care programs is 35 in the central office here in Washington and 50 in the regional offices.

We believe with the staff already in place in both the central office and regional offices, we can administer the CHAP bill with an additional 14 staff.

Mr. DANNEMEYER. Then those are the questions that I have asked for Dr. Carter.

I have some questions of my own. How does this bill relate to the legislation that Senator Cranston from my State of California has? Is it similar to it? Am I thinking about something else?

Dr. DAVIS. I am not quite certain of the specific legislation proposal that you have in mind. I believe that Senator Cranston has a variation of the CHAP proposal in the Senate.

Title II of the CHAP bill would cover pregnant women and I believe he has introduced that as a separate piece of legislation.

Mr. DANNEMEYER. I was not here at the beginning of your presentation, and can you tell me what the cost of this program is projected to be in the first year?

Dr. DAVIS. For the administration's bill, we estimate that the Federal cost in fiscal 1980 will be \$278 million.

Mr. DANNEMEYER. And then do you have projections on the cost for the next couple of years there?

Dr. DAVIS. In fiscal 1981, the Federal cost of the administration's bill will be about \$560 million, which is the first full year of implementation of the program.

In fiscal 1982, it will be \$752 million.

Mr. DANNEMEYER. Aside from the need question, which no one can quarrel with, that is to provide children of this country with the best possible health care that our system can provide, I am not sure it is appropriate on a committee policy such as this subcommittee is to go into the question of whether we can afford it or not, but for me to fail to ask that question of you as performer of this message I think would be irresponsible on my part.

When you reflect that we have 30 States in the Union currently telling the Federal Government to get its fiscal house in order, does it really make sense for any administration, or for either political

party, to talk seriously about embarking upon a program, the merits of which aside, which in the first year as you have indicated, will cost a \$250,000 and next year \$500,000 and the next year \$750,000?

The American people are asking where is the money going to come from, and I am going to ask you: Where do you think we are going to get the money?

Dr. DAVIS. It is useful to look at the proposal in the context of the administration's overall health policy. The administration has made a commitment to try to eliminate waste in the health care system, to improve the efficiency of the operation of Government programs, and to really try to realize savings by changing our current health care system from one in which all of the incentives are for inpatient care and increasingly costly hospital care, to one which puts more of our health resources into preventive and primary care.

More specifically, the administration has proposed hospital cost containment legislation which would reduce Federal outlays over a 5-year period by about \$20 billion.

Certainly, only a small fraction of the savings under that one piece of legislation would be required to provide the kind of expanded services that are mentioned in this bill. We feel that this is one of the most vulnerable and needy groups in our society, children and pregnant women below 55 percent of poverty. Also the main emphasis is on preventive and primary care, and we feel this kind of balance, trying to keep some economies on the administrative side and institutional side, and then putting more resources into the primary care side, is the kind of overall health policy we ought to be promoting in this country.

Mr. DANNEMEYER. If I hear you, those are certainly competent remarks. I come from a State where I think our medicaid program has done an outstanding job of bringing health care to people. I cannot quote you statistics, and I am a former member of the legislature in California. I did not serve on health care, but I have a little knowledge of that area, but it is my understanding that in my home State of California that any citizen, adult or child, in need of health care can get that needed health care under existing medicaid programs if they do not have the means to provide it themselves.

That being my perspective as a member of this house from California, I have to ask another question: Do we need yet another Federal program to advise the States how they can address the responsibility which is very real, that is, to assure or look after the health care of the citizens of the several States?

Dr. DAVIS. I am not sure of the experience in your particular district, but I think the State of California is a good example of why we do need this type of legislation.

It is true that the State of California has covered many low-income people and has done a much better job than most in terms of the proportion of people covered. But our statistics indicate that only 10 percent of the medicaid children in the State of California are currently screened under these programs. That State has not been successful in reaching a high proportion of eligible children and assuring that they receive preventive services.

We think it is important to put more emphasis on this; to provide incentives to States through a higher match to improve their performance. We think there are many deficiencies, particularly in getting children in for preventive continuing care and assessment.

Mr. DANNEMEYER. Thank you.

Mr. MAGUIRE. Mr. Leland.

Mr. LELAND. Mr. Chairman, I would like to take care of a house-keeping matter.

Your proposal calls for an increased Federal fund matching rate, and I am curious as to the problems of attracting providers to the EPSDT program. What, in your bill, overcomes the historical problem of getting these ongoing care providers to participate in the program?

Dr. DAVIS. There are two things that the bill would do. One, it does require the States to make assessment services available by all qualified physicians and health care centers that choose to participate. Many States currently use only their county health departments to do EPSDT screening.

For example, the State of Texas does not currently reimburse physicians, who would want to provide screening or comprehensive physical assessments.

So our bill does require the State to permit physicians, primary care centers, and rural health clinics and other organized settings to become assessment providers or continuing care providers should they choose to do so.

The second provision in the bill which addresses this issue gives the Secretary authority to set methods of reimbursement and reimbursement rates that would be attractive to providers. Those could be minimum fees they could be capitation rates or they could be bonuses for particular services.

So we have tried to address it both by requiring the State to deal with a wide range of providers, many of whom are interested in providing this service, and also by addressing some of the reimbursement difficulties.

I might also mention that one of the administrative complaints of physicians has been the claims processing. We have in this bill mandated a uniform 1-page claims form that would include the assessment on one spot and treatment on the other.

So, we are trying to deal with that. I know the Health Care Financing Administration has been meeting with a number of the professional associations to try to identify their specific concerns with EPSDT programs; what areas prevented them from participating in it and trying to address those.

Mr. HEIM. Yes, it is correct. In meeting with provider groups, I think that there are two problems. They consistently bring up the problems of fees and forms. The fees are too low and the forms are too many and too complicated, and so I think the approach that the administration is proposing is to provide incentives in terms of continuing care providers, to pay them to take on the extra responsibilities for case management and then, second, to address the problems of many and complicated forms, to mandate on the States a uniform claim form for treatment of children.

Mr. LELAND. Is there any particular comment that you have about the reason that Texas is somewhat unique in comparison to other States?

Dr. DAVIS. I think there are different reasons for various States. I am familiar with Texas because I lived in your district in Houston for 10 years.

Mr. LELAND. That is right.

Dr. DAVIS. I am very concerned about the performance in that State. I think sometime there is a feeling on the part of States that it is much cheaper to use the county health departments. Then you have Federal funding on a matching basis to cover the costs of the screening by a State or local organization.

So, it does provide some relief to the State and local funding of county health departments if the Federal Government will channel its money into a State or local agency.

But I think that this approach does limit access to the service. Many families will not come in contact with those county health departments, and will only seek out care when they are sick or have another child who is sick, so it leaves them without benefit of full implementation.

Mr. LELAND. Can you expand on that and deal with the question of outreach and what provides for some incentives for outreach in your bill?

Dr. DAVIS. Our bill does increase the match on outreach services to 75 percent when that outreach is performed by private organizations or by State or local public agencies. We were impressed by many of the people who testified before this committee on outreach activities and feel that it is a very important and essential service.

Mr. LELAND. To stay in Texas for a minute, I understand we have the very highest percentage of new recipients. I think it is about a 99.5-percent increase.

Ms. MIKULSKI. Did you say "new" or "nuke?"

Mr. LELAND. I have no comment.

Dr. DAVIS. I think of the 2 million new eligibles, I think about 280,000 of those are in Texas, which is more than any other State. Illinois is second with over 200,000 new patented eligibles.

Mr. MAGUIRE. Which means that Texas has been doing a lousy job.

Mr. LELAND. And the CHAP cost is very high. Will you explain that in comparison with other States?

Dr. DAVIS. For that State we would be bringing in a substantial number of new children and pregnant women. We estimate that in 1980 overall the States will be paying about \$58 million in additional costs to pick up their share of expanded eligibles. The State of Texas would be asked to pick up about \$16 million in additional funds in 1980.

That represents about 4 percent of their current medicaid expenditures. So, in 1980, for Texas there would be a \$16 million increase in State cost. It is a fairly small share of the total medicaid program.

Again, with the performance match in the out years, should some States reach a much higher fraction of the children than they currently reach, the higher match would offer some offsets to these costs if they were to do a good job in improving their programs.

Mr. LELAND. Thank you.

Let me just ask you about the bill H.R. 4362 [see p. 312], that I and Chairman Maguire have just introduced. It is a complementary piece of legislation to CHAP and it deals with the prevention of maternal childhood nutritional disorders prevention. It is called the Maternal and Childhood Nutritional Disorders Prevention and Information Act.

I realize you have addressed the question of nutrition and nutritional counseling. Can you address to the issue of nutritional necessity in the area of child care, hopefully supportive of my piece of legislation, in general terms until you have had time to scrutinize the bill, to comment on the need.

Dr. DAVIS. We do feel that nutritional counseling is very important. We do include nutritional counseling as one of the elements in the CHAP assessment package. It has been my experience in visiting a number of health centers in the rural south that improved nutritional efforts can in fact have a very marked impact on health status.

For example, in one particular health center that I visited in Arkansas, they had a WIC, woman and infant care feeding program, from the Department of Agriculture that was a service provided by the health center. When the center started providing this service, the death rates from gastrointestinal diseases in infants really plummeted.

This county, which had a 60 percent black population with the highest poverty rate of any county in the State, had an infant mortality rate lower than the State average. The center related this to the fact that with the WIC program and prepackaged formula; infants were not subject to the kind of bacteria from improper sterilization of bottles that had lead to gastrointestinal diseases, dehydration and death.

So, this service, along with the range of health services, was extraordinarily important in improving health status.

The Department has been working with the Office of Management and Budget and the Department of Agriculture to try to improve the coordination of health programs and nutritional programs such as WIC, and the community health center and maternal and child health programs.

I know that this is one element of your bill and that is one step that we are trying to take. We are very interested in some of the ideas that you have with regard to information and advertising through the Federal Trade Commission and research centers in this area and we will certainly look carefully at your bill.

Mr. LELAND. That is fantastic. Thank you.

Mr. MAGUIRE. Congresswoman Mikulski.

Ms. MIKULSKI. I come from a State, Mr. Leland, that ranks 49th in enrolling eligible children in the early detection program, so it is not only Texas which has problems.

Mr. LELAND. I am sorry.

Ms. MIKULSKI. I think we have more cars in parking lots of Government agencies than we have children in our health care program.

Dr. Davis, I have two questions. I am concerned whether or not States will be reimbursed for children when there is a need for

State institutionalization. What I mean in this particular instance, I think you are familiar with the concepts of children in need of supervision, children who need to be placed either in foster care or very often in institutional care.

It might be a Maryland training center, one of the juvenile training type facilities. Very often those are the poorest kids, very often from neglectful and orphaned and violently abused circumstances.

What I am wondering is: When a child would move from his or her own home into some type of institutional supervision, whether their care would be reimbursed under this legislation?

Dr. DAVIS. That is not included in our legislation. I believe it is included in some of the other alternatives.

Ms. MIKULSKI. It is not included in the administration bill?

Dr. DAVIS. No; in looking at that, we found that for the most part the States are currently providing medical care to children in these institutions and were we to cover it, it would be largely a substitution of Federal funds for State funds and, perhaps be less of a priority for the limited dollars, so we did not cover it.

Ms. MIKULSKI. The next question I have relates to who provides who with what. In looking at the legislation, it seems that we reinforce traditional models of health care delivery. That is, we usually confine this primarily to physicians. I am a believer, for example, in the mental health sector. I am a social worker and I know the role that social workers can play in the field of mental health or psychology and I know, for example, the role nurses, practitioners and/or midwives can play in maternal health care.

I am wondering, and I raised this issue with Mr. Califano, if you had the opportunity to think about how you could expand your bill to include reimbursing other kinds of health providers. A lot of these, I think, provide a way of dealing with the cost issue without diminishing the quality of health care.

Have you thought about making changes along those lines? Right now, reimbursement, generally for medicaid, reinforces the traditional model.

Dr. DAVIS. The Department is anxious to go beyond traditional providers and encourage the use of nurse practitioners and nurse midwives.

For example, in the rural clinic bill, we now pay under medicaid and medicare for services of nurse practitioners, physician assistants and nurse midwives when they provide services under the supervision of a physician, although that supervision need not be on-site.

So, we have started paying not the practitioners directly but rural clinics that hire such practitioners. Under this bill, we would also pay not just physicians to be continuing care providers but rural health centers and community health centers and health maintenance organizations and other organizations that hire these types of health professionals, so that their services would be covered under the bill.

Let me speak a little bit more specifically to the mental health issue.

Ms. MIKULSKI. Before we move to that, could we stick with this because I want to be sure I understand the concept. What you are

saying is that you have two types of reimbursement. One is directly to a human provider rather than an institutional provider. That would be a physician.

But where you reimburse institutions which would provide service, the patients can choose whatever they want. They could experiment and they could be innovative and there could be a pluralistic approach to this. So, if we reimburse the health center, like the Calder Center, it can deliver whatever modalities it cares to as long as it meets State standards.

Dr. DAVIS. That is right.

Ms. MIKULSKI. I did not mean to curtail your answer.

Dr. DAVIS. On the mental health side, we also cover the community health centers that are funded by the Department through its mental health activities and we also provide or cover other certified mental health centers.

So, again, it is a matter of paying the organized setting for services that may be provided within that organization by psychiatrists and psychiatric social workers and, again, in various kinds of teams or under various kinds of arrangements. We would pay the community mental health center as an organization, plus covering psychiatrists as physicians, so that the services would be covered but in organized delivery settings.

Ms. MIKULSKI. I read all of these analyses and briefs and I was trying to get a picture of what it would mean to be a kid or to be trying to get a kid in this program. Could you give me a scenario? If I were a mother, whether in Texas, or New Jersey or wherever, and I wanted to get into this, what would happen to me and where would I go and how would I know about it?

Where would I go and what would happen to my little Max or Maxine once we walked into some type of facility?

Dr. DAVIS. If you were low-income and receiving cash assistance, you would be advised by the case worker.

Ms. MIKULSKI. I would be 55 percent below the poverty line?

Dr. DAVIS. If you are on cash assistance in the AFDC Program, you would be covered even if that State covered children above the 55 percent level and you would be informed of the program through that mechanism. If you were below 55 percent of the poverty level but were not on cash assistance, perhaps you had both parents in the home and did not qualify in that State for AFDC coverage, we would try to make sure that individuals were informed of this program, as I indicated earlier, through various kinds of publicity.

For example, if you were on Food Stamps, and you could get information and leaflets through that program. If your child became sick, it would also be likely for your physician or hospital to point out that you could get financial assistance in paying bills by signing up for this program. There are various ways you could find out about the program.

Once you were eligible, basically you sign up for the program through the State agency administering the medicaid program, which is largely through State or local welfare offices at present, so your intake eligibility is through that system.

When you have a medicaid card the child is entitled to the full range of medicaid services and hospital services, plus the new

services that we mandate under this bill, including dental care. Since you would have a medicaid card you could go to any physician who would take medicaid patients and your bills would be paid through that.

We would also try to encourage more physicians to be continuing care providers so that they would take the responsibility for maintaining a medical record on that child, following up and making sure that the child was referred to specialists when needed and providing comprehensive health assessments.

CHAP coverage is not just treatment for an acute condition but get preventive physical examinations as part of that.

Ms. MIKULSKI. I am still worried that we are not going to get or reach the kids and this fear is not to demean the efforts you have described. I wonder if there should be some targeted effort using the schools, just because about every kid has to be enrolled in either private or public school.

Would you say that is an important base to this, or maybe one of the linchpins in delivering this service?

Dr. DAVIS. Yes, we do include schools as providers who can do assessments. That is in the bill. It is one of the ways in which children could get into the system, be assessed, and find out about this program.

There is also a serious problem, though, for preschool children. We find very low immunization rates, for example, in the preschool age groups. There we would work with Head Start centers, and with a variety of program and organizations to try to find those children and get them into the program.

As we mentioned earlier, we are also increasing the match for outreach services to 75 percent to try, either through private organizations or public agencies, to find more of these children and get them into care. But we have included as eligible assessors a wide range of organizations that deal with children.

Ms. MIKULSKI. Thank you.

The chairman is more than generous. Thank you.

Mr. MAGUIRE. Thank you. We have been joined by the ranking minority member.

Mr. CARTER. Dr. Davis, I have a question. Would this legislation require pediatricians to sign agreements for caring for children?

Dr. DAVIS. It would not require the pediatrician to participate in the program. We have been working with the American Academy of Pediatricians to identify ways to improve provider participation.

Mr. CARTER. I mean, if they did, would they sign agreements?

Dr. DAVIS. We do require written agreements. Basically, there are two kinds of written agreements. If a provider wants to assess children, we would ask them to enter into a written agreement saying "We understand what the components of the comprehensive assessment are and we agree to provide that package."

If they want to be a continuing care provider where there are certain special incentives, they would have to say:

I would agree to be a continuing care provider and I will keep a medical record on that child and I will see that she gets regular physical examinations and I will see that she gets referred to a specialist and I will be available to that child or the family by phone in the matter of emergencies.

Mr. CARTER. Does that cost much money?

Dr. DAVIS. The legislation indicates that the Secretary could set minimum standards for adequate reimbursement; there could be bonuses for being a continuing care provider and for providing case management. The program could provide various kinds of incentives to physicians to participate.

One of the main problems, as I think you know, is that many of the fees set by States have been so low that physicians have not chosen to participate in the program. We can make sure that these are adequate to attract physicians and also try to get for low-income children the kind of ongoing care that most pediatric practitioners provide for more affluent families.

Mr. CARTER. There would be a fee system and would you pay according to that?

Dr. DAVIS. Yes.

Mr. CARTER. I notice that you have lowered the poverty level a little bit. Inflation has increased and I would think that the poverty level would have risen. What is the level at which poor children would receive care?

Dr. DAVIS. In our bill we set the income standard at 55 percent of the Federal poverty level. In 1980, the Federal poverty level for a family of four is roughly \$7,500, so we would cover below \$4,100, or 55 percent of that.

I believe your bill, Dr. Carter, covers all children up to \$4,200. One difference between our bill and your bill is that ours is automatically indexed in future years, so that if the poverty rate goes up with inflation, we would continue to raise the income level to 55 percent of the Federal level.

Mr. CARTER. We had that intention there but ours begins a little higher at \$4,200, so it would take care of more children. The authorization is a little higher; I believe it is higher than that of my distinguished chairman.

Mr. MAGUIRE. We take care of another million.

Mr. CARTER. There is no doubt that you would. I would not disagree with that, Mr. Chairman. I think for poor children CHAP is good legislation. I think we can find out what defects exist and, if we correct them, we will save that child ill health, suffering sickness, and his family money. We would be compassionate also.

I have been a physician and it is extremely helpful for the dentist to check the child. This is included in your legislation, is it not?

Dr. DAVIS. Yes.

Mr. CARTER. That is regular dental care.

Dr. DAVIS. Yes.

Mr. CARTER. I think that is extremely important, and for poor pregnant mothers with the same income level.

Dr. DAVIS. Yes.

Mr. CARTER. I think it is good legislation. Thank you, madam. It is a little short in places, and it is not unusual to see an administration bill which is.

Mr. MAGUIRE. Dr. Davis, we are running short on time here and I would like to ask a couple of additional questions if we can and then quickly move on.

I am concerned about case tracking. I want to find out more about continuing care. I want to go back to the data collection and

do all of that in 5 to 10 minutes. CHAP, like EPSDT, calls for States to have in place case tracking capabilities.

Now, do the States have the case tracking and case management sufficient to do the job that the bill will require?

Dr. DAVIS. I would like to ask Mr. Heim to answer that.

Mr. MAGUIRE. Maybe that takes us back to the data question. But my understanding is that a lot of States have been working out of pasteboard boxes and the data becomes very important, not just with respect to reimbursement, but also with respect to whether the job is being done with children over the life and time of their years in the program. As Ms. Mikulski was indicating, she was concerned.

Mr. HEIM. Unfortunately, what you describe has been the case in a few States. But more and more or almost all States have some sort of computer capability now for claims payment. We presently have 25 States that have certified medicaid management information assistance that meet the Federal criteria for such systems.

We expect to have about another half dozen certified by the end of this year. By the end of next year, if our present schedule holds up, we will have between 90 and 95 percent of all the program dollars covered in States with a medical management system.

Any State with a medicaid management system should have the capability to track this program, either the current EPSDT program or the proposed CHAP legislation. I should also like to add that I think a key to a good tracking system is the proposal in the bill for a uniform claims form.

So, it will be possible to collect all the data on each child of everything that has been performed for that child in terms of ambulatory care.

Mr. MAGUIRE. That is excellent. You played right into my hands, and let me ask you the next question, which is: If we are going to be so well off with 90 to 95 percent of the program dollars in areas where you have certified computerized data banks on a child-by-child basis, then why on earth, Dr. Davis, do we not reimburse people based on a child-by-child analysis of actual assessment, people actually being screened and given followup treatment and continuing care, rather than this rather curious system that you described earlier where people will receive higher reimbursements as a result of a ratio between those that are assessed and those that are enrolled, which has those negative consequences we discussed earlier?

Why can't we do it on a child-by-child basis as my bill provides?

Dr. DAVIS. I think the objective in both bills is really the same: to give an incentive to the States to improve their performance and to see that children get good care. One basic difference between the way we would structure the performance match and the way that you structure the match is that you would give a higher Federal match for just getting a child assessed, even if that child were not treated, and even if that child did not have continuing care. We would gage the match on both getting the child assessed and treated, or under a continuing care arrangement where a physician or health center would be responsible for that child's care.

Mr. MAGUIRE. You may have improved on my bill in that respect but that does not deal with the fundamental question, which is:

Why can't we then reimburse on a child-by-child basis for assessment or, if you want, assessment and treatment and ongoing care, so that every child that is added in is a plus for the State rather than having a situation in which the proportion of children that are being taken care of is measured against the number of children who are enrolled?

Your bill does not provide that that measure would take into account the number of eligible people out there; only those actually enrolled. The result that getting them enrolled becomes the subject of at least some disincentives with respect to reimbursement.

Let me give you an example. If you have 6,000 eligible children in State "A," and 6,000 eligible children in State "B," and you are also serving the same number, let us say 1,000 in CHAP and 1,200 more in continuing care. That is 1,000 CHAP and 1,000 ongoing care, which you evaluate at a 1.2 factor, let us say it is the same in the two States.

But the difference is that in State "A" you have only 5,000 of the 6,000 eligible actually enrolled, whereas in State "B" you have all 6,000 of the 6,000 eligibles enrolled, and look what happens. In State "B" where you have 1,000 more children actually enrolled you get a .36 reimbursement factor, whereas in the State that has done less well and has enrolled 1,000 less children, even though they may be assessing the children and treatment them at the same level, they get a higher ratio, 0.44 reimbursement ratio.

I do not know why, if we are going to design this thing rationally, why we would build in that kind of a weakness. If you have the data, as Mr. Heim has indicated, on a child-by-child basis for almost the universe, why don't we do it on a child-by-child basis?

Dr. DAVIS. I think there are different ways of trying to structure a financial incentive.

Mr. MAGUIRE. I know, but some are better than others.

Dr. DAVIS. I really do not feel that there are going to be serious disadvantages to nonenrolled children.

Mr. MAGUIRE. But it is there in black and white. You get less money if you enroll more people.

Dr. DAVIS. This approach is also in your bill. You have a bonus that increases the Federal payments for administrative costs by 25 percent if the State had better performance with standards based on the proportion of eligibles who are treated and immunized. Thus, you have factors in a denominator that reflect a proportion of eligibles.

The administrative expense is high in improving performance and in terms of expanding eligibility as well. But as I said we can look at the different approaches. We made a careful judgment of and in our opinion it is not a serious problem to gage performance in terms of what proportion of the children who are eligible get continuing care and are treated.

We feel that it is somewhat simpler administratively, namely, the child under your proposal goes to a physician in February but she is not yet assessed; then she is assessed in March and then goes back to the physician in April. The State gets a higher match on the visit in April than it got on the visit in February, but the bill for the visit in February may come in in May. It seems simpler to use our approach.

Mr. MAGUIRE. You said my bill also had these performance criteria in terms of ratios. But we use the number of eligible people to measure performance against, which is the constant thing. It is not the number enrolled. Perhaps we can discuss this further because I think it is a very important point and maybe we can come to a meeting of the minds on it.

Let me turn for my final question to the continuing care provider which is a very interesting and innovative notion in your bill. I think you started a moment ago to give some examples of what a continuing care provider would do.

Would you tell us a little bit more about how exactly you would define one and what standard you might be thinking of for reimbursement of the continuing care provider; you indicated what standards and ratios you would use for CHAP earlier, and perhaps you can give us the same rundown on the continuing care provider.

Dr. DAVIS. The basic idea of a continuing care provider was a normal family practice physician and primary health care center and what they would do.

Mr. MAGUIRE. It is or it is not?

Dr. DAVIS. It is basically the same. What we would require of a continuing care provider would be a written agreement to be responsible for a special child like Mary Jones. The continuing care provider would provide directly the periodic health assessments.

In other words, all of the things required like history and physical examinations and diagnostic tests and immunizations. This continuing care provider would agree to provide an assessment including all of these components. They would notify the family at various intervals when an assessment or preventive service was due.

In addition, a continuing care provider would treat the medical conditions that were found during an assessment or during any kind of a visit, to the extent that this provider was able to provide that range of services. But when a child required specialized care, that could not be provided by that physician or health center; the provider would refer her to another provider who is able to provide appropriate treatment services and would follow up on that care.

The physician would ask the specialist: "Did the child come in and what did you find?" And he would add that information to the child's medical record. Then a continuing care provider would be available to the family, so that you could at least get in contact with the physician or referral service of that provider by telephone.

A continuing care provider would maintain a record of the findings, corrective measures and other health services, in effect, keep a patient chart on that child. That is, that the provider would contact the medicaid CHAP Program if the child was missing an appointment or missing two appointments. the provider would also contact the family by phone and so on.

Those are basically the kinds of things that we would expect the continuing care provider to do.

In terms of reimbursement, the legislation does give the Secretary of HEW authority to establish methods and levels of reimbursement for the services of continuing care providers. They would take into account some of the higher costs of providing good ongoing care. There could be minimum fee schedules; there could

be a case management bonus and there could be capitation of prospective payments.

These are all possible reimbursement options for continuing care providers.

Mr. MAGUIRE. You do not have any specific numbers or percentages to present to us?

Dr. DAVIS. No, you might have different costs for practices in different areas of the country so you might want to set rates at somewhat different levels in different parts of the country.

Mr. MAGUIRE. All right. There are two things that concern me about this. One is how do we know we are not just going to get additional paperwork with no effect? Do we have any demonstration projects or any data that suggests that what you are proposing here is actually going to be a sufficient incentive for people to sign up for this program?

Dr. DAVIS. We are engaged in a number of demonstrations, largely funded through the Health Care Financing Administration. They are currently planning demonstrations, for example, to look at some of these prospective capitation methods to gain experience with this approach.

There are always, in any new program, a lot of unanswered questions about what the full implications of the program would be. We are planning demonstrations to help us learn and to get more experience, early on. But we feel that the need is so acute and that this is such a serious situation, that if you waited until you studied every possible aspect of the program, you would not be getting those benefits for children.

Mr. MAGUIRE. I share your hope that as many people as possible who are providing care enroll in this way and as many children as possible are served in this way. But I am wondering where it leaves us, particularly if the numbers that become involved in the continuing care program are not that great, when in your bill you do not require ongoing case management for the CHAP provider specifically.

That is, the CHAP provider that is unassociated with the continuing care segment of your program. In our bill we do in fact require ongoing case management for any provider in the CHAP program. So, what would be your comment on the potential weakness that that might demonstrate in your approach?

Obviously, there will not be any weakness at all if everyone signed up for continuing care, but in case that does not happen, then you do not have case management covered very well, it seems to me, for the thousands of people involved.

Dr. DAVIS. We would like to promote the continuing concept as far as we can and get as many people under continuing care as possible. However, we did feel it was important to get the children assessed and to the extent possible good followup on treatment of conditions found on assessment.

We would work with the schools and Head Start agencies and other organizations that may not be capable themselves of doing all of the followup and case management. So, in those instances, we would rely upon the States to perform some of the case management functions.

Mr. MAGUIRE. Can we get some minimum criteria in there for case management of those who are not included in the continuing care program?

Dr. DAVIS. You might want some performance standards such as what proportion of the children can be assessed and that were getting treated or that kind of thing.

Mr. MAGUIRE. And would you think that it might be appropriate to extend the reimbursement incentives that you provide for continuing care to other kinds of providers, such as dentists?

Dr. DAVIS. That is a possibility. We really did not look specifically at the reimbursement issue in the case study.

Mr. MAGUIRE. Are there any other questions?

Thank you very much. We appreciate your excellent statement. The subcommittee will recess until 1:30 p.m.

[Whereupon, at 12:10 p.m., the subcommittee was recessed until 1:30 p.m. the same day.]

AFTER RECESS

[The subcommittee reconvened at 1:30 p.m., Hon. Andrew Maguire, presiding.]

Mr. MAGUIRE. The subcommittee will resume its consideration of the child health assessments program.

Our next witness is Judith Weitz, program specialist on health at the Children's Defense Fund, accompanied by Wendy Lazarus, a consultant to the fund.

STATEMENT OF JUDITH WEITZ, PROGRAM SPECIALIST/ HEALTH, CHILDREN'S DEFENSE FUND, ACCOMPANIED BY WENDY LAZARUS, CONSULTANT

Ms. WEITZ. Thank you.

I am Judith Weitz, a member of the health staff of the Children's Defense Fund (CDF). With me is Wendy Lazarus who is currently a consultant to CDF and before was director of the CDF's nationwide study of the EPSDT program.

As you know, in 1977 we published a record on EPSDT based on our 2-year study of the program. Probably the single toughest issue we faced after finishing the study was whether or not it made sense to build on this program which has a poor track record. After extensive consultation, our conclusion was that if the goal was to get the most health care out to the most children in the quickest way possible it made sense to build on it. The program is in place nationwide and with relatively straightforward legislative changes it can move swiftly to provide care to millions who now receive none.

People in Congress and outside groups sometimes ask: Given the poor record HEW has in getting the EPSDT program to work, is there any reason to believe that CHAP will do any better? We believe it can and that it will.

First, there will have been a much more extensive airing of the problems of mounting a program like CHAP as the basis for writing the legislation than there ever was in 1967.

Second, as a result the legislation will include more explicit language on the program's purpose and how that will be achieved.

HEW will have neither an ambiguous charge nor the excuse of a vague legislative mandate.

Third, there is a much more informed constituency out there. People eligible for services are more aware of the program and what they should be receiving through it. There are more outside groups interested in monitoring and promoting the implementation of CHAP than before.

Fourth, Congress is more aware of the need to oversee the program, both H.R. 2461 and H.R. 2159, include provisions for congressional oversight.

Finally, HEW has had more experience in administering the program.

CHAP's goals, although relatively modest, are crucial: modification EPSDT to enroll all needy low-income children in a system health care; assurance of complete preventive services and necessary subsequent care for eligible children; and correction of the most serious inequities in eligibility and benefit policies for children and youth under medicaid.

Certain modifications are necessary to accomplish these purposes. Many of those are administrative changes which can be accomplished easily and with little or no cost. The remainder require funds but indeed modest increases, particularly given the evidence that preventive care brings cost savings.

All three CHAP proposals contain many important provisions. The administration's proposal is a significant improvement over its previous one. In many respects the three bills offer similar solutions to the major problems. I want to underscore our support of the many goals and provisions common to the three bills. While we will submit for the record an analysis of the administration's proposal, I want to touch briefly today on a number of the key areas where the bills differ.

First, in the area of provider participation. You know, a chronic problem has been that few States have used the full range of providers qualified to offer EPSDT services. In some places children cannot receive services from the very providers which can meet their needs best. Currently approximately 17 States rely on county health departments to the exclusion of other high quality providers.

CHAP should require States to actively solicit participation in CHAP and offer written agreements to all qualified providers on terms which can be expected to elicit their involvement. And, HEW should be charged with monitoring State performance and with reporting to Congress on provider participation in CHAP and the steps being taken to use all qualified providers.

One of the main reasons providers have been reluctant to participate in EPSDT has been that the administrative responsibilities are demanding. Under CHAP those responsibilities are greater. Yet, in the administration's proposal the Federal share of cost for case management and followup remain at the current level. To induce providers to participate and to develop the badly needed case management capabilities, increased Federal reimbursement for followup must be made available to States and the cost of follow up must be included in the reimbursement rates negotiated with providers.

CHAP charges States with developing many services and seeing that children receive them and this calls for a very different kind of planning and different kind of capability than other medicaid provisions. States must have a strategy for meeting program goals and we advocate requiring States to develop with public input an annual State plan demonstrating the capacity to meet program requirements.

In the area of financing, increasing the Federal share of expenditures for ambulatory care services is very important. All three of the proposals do that. We have concerns about the administration's approach. Because the relationship of State performance to financing is not spelled out in the bill, the impact of this approach is not clear.

Will this system be an incentive to States to mount effective programs? Will it even adequately cover the cost of performing at any given level? Nor is it clear whether the performance standards will be set at a level which indicates adequate performance. To the extent that they do not measure program adequacy, CHAP will provide increased Federal support for an inadequate program. If the provisions in the administration's bill are adopted by the subcommittee, the details must be worked out in CHAP in a manner which guarantees a workable and efficient system of financing.

Outreach we all know is the first crucial step in the program and if it is not done effectively no child will benefit from CHAP. So, this is very important. However, as we know from experience, the availability of Federal funds does not lead States to institute programs. Since each child brought into the program represents an expenditure for the State, it is not in the State's financial interest despite higher Federal reimbursement rates to bring additional children into the program. Therefore, we recommend including in any CHAP bill the provisions in H.R. 2461 which require States to earmark a portion of the program budget for outreach services.

CHAP must also build in ways of shifting outreach activities away from the heavy reliance on welfare agencies. It should promote the use of community organizations which employ trained paraprofessionals who are from the target community. CHAP should require States which do not reach a reasonable portion of eligible children to develop outreach programs emphasizing the use of organizations located in the target community.

In the area of health services, the benefit package, the purpose of a primary care program is, after all, to prevent and to treat early on children's health problems. For CHAP to identify a child's health needs but not provide the service to treat the problem defeats the very purpose of the program.

We strongly support the administration's provision which makes the expanded package of service available to all medicaid children regardless of whether or not they have received a health assessment. However, if the benefit package itself in the administration's bill is adopted, many children—particularly children with handicapping conditions—will be without care.

States can opt not to cover a range of health services, such as speech therapy and physical therapy, which children need. Children will not necessarily be able to get these services through other programs for other federally funded programs reached a very small

portion of the CHAP children who need their services and many of these programs rely on medicaid for financing. CHAP should include at a minimum coverage of all needed ambulatory care, including outpatient mental health services, for medicaid-eligible children without limitations on the amount, duration, or scope of these services,

There is a wide consensus that children need routine dental care. Again all the CHAP bills include dental benefits. Despite this expansion, however, children will still go without services unless CHAP assures the availability of dental providers and explicitly and appropriately delegates responsibility for referral and followup on referrals for such care. CHAP should make direct referral to a dentist a provider responsibility and specify responsibility for followup on such referrals to assure the children are getting the care for which they were referred.

Finally, while we support using incentives, when States do not meet standards we should have ways of accomplishing compliance with the law. In H.R. 4053 enforcement is accomplished through the financing system.

Now the effectiveness of any compliance measure depends on the level of performance which triggers the enforcement mechanism and the impact of the penalty for not performing adequately. It is doubtful the administration's approach will have sufficient impact to bring about compliance. In some States it will be cheaper to absorb the reduction of the Federal matching rate for ambulatory services than mount an adequate CHAP program.

Second, since the reduction in the Federal match is applied to expenditures for ambulatory care services for children which comprises a fraction of overall cost, as opposed, for instance, to inpatient care, it is less likely to have an impact on State performance.

Third, since the reduction is applied to service related funds, it is more likely to be harmful to program beneficiaries. CHAP should establish a minimum level for purposes of determining whether a financial penalty should be applied. States not meeting this level should receive a substantial reduction from in the Federal share of medicaid administrative costs.

Given the general consensus represented by the three CHAP bills on what needs to be done to reform EPSDT, the subcommittee should be able to act on CHAP quickly and we urge you to do so. Time is getting very short. Please let us not again lose the chance to enact this legislation. Low income children who were not yet born when EPSDT was enacted in 1967 are now nearly 12 years old. These children must not go still longer without basic health services.

Thank you.

[Testimony resumes on p. 128.]

[The following information was received for the record:]

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THE CHILD HEALTH ASSURANCE ACT OF 1979:A BRIEF ANALYSIS OF THE ADMINISTRATION'S CHAP PROPOSAL

On May 10, 1979, President Carter sent Congress a new proposal to strengthen and improve the Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT), and to broaden Medicaid eligibility for children. The bill, called the Child Health Assurance Program (CHAP), is a revision of the one submitted to Congress by President Carter in April, 1977.

While both the House Interstate and Foreign Commerce Committee and the Senate Finance Committee reported out CHAP bills last session, Congress adjourned before final action could be taken. As a result of last year's efforts, however, interest in and momentum for getting legislative reform of EPSDT is strong. President Carter has listed passage of the new CHAP bill as one of the Administration's top priorities and only initiatives in health this year. Furthermore, a broad range of outside interest groups support CHAP legislation and CHAP has bi-partisan support in Congress.

The new CHAP proposal makes a variety of changes in EPSDT and Medicaid which affect individuals under age eighteen including changes in: eligibility; benefits covered; financing of services; and the administration of the EPSDT program. We endorse many of the goals and provisions in the Administration's new CHAP bill and we believe it is a significant improvement over the Administration's bill of last year.

Specifically, the Administration's revised CHAP proposal would:

- o Include in Medicaid additional children who are not currently on welfare but would qualify if income alone were the basis of eligibility.
- o Include in Medicaid additional low-income pregnant women.
- o Establish a national minimum income level for determining the eligibility of children and pregnant women.
- o Provide for a clearly defined, comprehensive health assessment, rather than a health screening.

- o Provide an expanded package of health services, including routine dental care, to all Medicaid - eligible children, regardless of whether or not they have received health assessments.
- o Eliminate cost sharing for Medicaid-eligible children for CHAP services.
- o Prohibit limits on the quantity of most CHAP services.
- o Extend a child's eligibility for Medicaid to help assure that necessary follow-up care is received.
- o Extend a pregnant woman's eligibility for Medicaid to help assure that needed prenatal and postnatal care is received.
- o Clearly define providers' and States' responsibilities under the program.
- o Provide incentives to States to encourage providers to offer routine forms of treatment and primary care as well as assessments.
- o Increase the federal share of costs for ambulatory care services for children, and for outreach.

Despite these substantial improvements, however, we believe that this new proposal lacks certain elements without which the reforms will not be as effective as they should be. For instance, this proposal does not assure development of effective outreach services by States so that families understand what services they can receive through CHAP. And, it is questionable whether the system of financing provides sufficient incentives for program expansion or that the monitoring and compliance procedures will be effective.

MAIN FEATURES OF NEW CHAP BILL

The Administration's revised CHAP bill would make the following modifications:

- o Require States to extend Medicaid eligibility to children under eighteen years of age in families with incomes below fifty-five percent of the Federal poverty measure or the State's income standard for Medicaid to a family with dependent children, whichever is higher.

(HEW estimates that this would make approximately two million new children eligible for Medicaid).

- o Require States to extend Medicaid eligibility to pregnant women with incomes below fifty-five percent of the Federal poverty measure or the State's income criteria for Medicaid to a family with dependent children, which ever is higher, for the duration of the pregnancy and for sixty days following the termination of the pregnancy.

(HEW estimates that this would extend Medicaid eligibility to approximately 100,000 more low-income women).

- o Require States to expand coverage of services for Medicaid-eligible children by including, in addition to those services covered under the State Medicaid plan, routine dental care, immunizations, vision and hearing services, prescribed drugs and insulin, and ambulatory mental health services delivered in Community Mental Health Centers and by other providers who meet standards established by regulation.
- o Extend Medicaid eligibility to children for four months following the date on which the income and resources of the family would otherwise make the child ineligible.
- o Set specific standards with which providers of assessments must comply and require that providers enter into written agreements with the State. Regular providers would be required to: provide periodic assessments; provide or refer children for basic diagnostic and treatment services; follow-up on referrals to insure the provision of services, or furnish the State with information to do follow-up; report to the State as required. Continuing care providers would be required to: provide periodic health assessments; provide continuing diagnostic and treatment services; provide continuing preventive and primary care; take responsibility for the medical case management of each child including providing reassessments as needed; report to the State as required.
- o Increase the federal match to States. During the first eighteen months, the federal matching rate for the costs of ambulatory care services for children would increase over a State's current rate by four percentage points. Subsequently, the federal matching rate for such services would be graduated for each State in relation to the State's performance in assessing children, providing care for conditions found, and providing continuing care. No State's federal matching rate would go higher than ninety percent or twenty percentage points above its current level nor lower than five percentage points below its current level.

- o Increase the federal match for outreach services to seventy-five percent. (Currently, the majority of these services are reimbursed at a fifty percent federal matching rate.)
- o Waive the application of the existing financial penalty for non-compliance (one percent of the federal share of States' AFDC payments) for all quarters before October 1, 1979. Repeal the existing penalty provision six months after enactment of CHAP.

MAJOR DEFICIENCIES IN THE NEW CHAP PROPOSAL

During the decade EPSDT has been in place, a great deal has been learned about the problems of the program and what is needed to make it work best for children. These lessons should be applied to the design of CHAP. We urge the following shortcomings in the Administration's proposal be addressed by Congress as it considers CHAP legislation.

Provider Participation

CHAP's clear intent is to make sure that poor children have ready access to CHAP services by involving the range of providers who are acceptable to poor families and qualified to give needed care. Medicaid law presently calls for EPSDT programs to make the maximum use of existing resources. However, the intent has not been carried out because the language is too general and the federal monitoring too lax. As a consequence, for instance, many states rely primarily on county health departments, to the exclusion of other qualified providers, to screen eligible children. In other states, qualified providers are effectively excluded from participating in EPSDT due to low reimbursement levels or inappropriate standards for certifying providers. Thus, children are denied access to comprehensive health centers and other providers which are often best suited to attend to their needs.

To remedy this problem, CHAP should require States to offer provider agreements to all qualified providers. These should include community health clinics, solo and group practice medical practitioners, day care or Head Start programs, rural health clinics, public health departments, maternal and child health centers, and any other entity that can meet responsibilities assigned to CHAP providers. CHAP should explicitly require States to identify all qualified providers, including dentists, and to encourage their participation in the program by offering administrative arrangements (including adequate reimbursement rates and prompt payment of claims) which can be expected to elicit their involvement. HEW should be charged with monitoring state performance in this regard and with reporting to Congress on provider participation in CHAP and the steps being taken to use all qualified providers in the program.

One of the main reasons providers have been reluctant to participate in EPSDT is that administrative responsibilities under the program are demanding. Many providers do not have staff to provide support services such as follow-up on referrals to see that needed care is received. Under CHAP, the responsibilities of providers are even greater. Yet in CHAP, the federal share of costs for case management and follow-up remains at the current level (generally at a fifty percent matching rate). To induce providers to participate and to develop the badly needed case management capabilities, it is essential that increased federal reimbursement be made available to States specifically for this purpose and that States cover the costs of follow-up in the reimbursement rates they negotiate with providers.

Financing

Increasing the federal share of expenditures for ambulatory care for children, including CHAP services, is a badly needed incentive for States to provide important basic care to children. We have, however, several concerns about the approach in the Administration's proposal. First, it is doubtful that the flat increase of four percentage points over States' current federal matching rate for ambulatory care services will cover the cost of an expanded program and provide the means or incentive to carry out necessary program changes. Second, while tying the financing of a program to performance is important, because the precise relationship of performance to financing is not spelled out in the bill, the impact of this approach is unclear. It is impossible to tell whether this system will be an incentive to States to mount effective programs or will even adequately cover the costs of performing at any given level. Nor is it clear whether the performance standards will be set at a level which indicates adequate performance. To the extent they do not measure program adequacy, CHAP will provide increased federal support for an inadequate program.

These details must be spelled out in CHAP in a manner which guarantees a workable and efficient system of financing.

Outreach

Currently, States are required to inform families with Medicaid-eligible children about the program and to encourage and help them use services. However, few States use the method of outreach proven to be most effective -- personal contact with Medicaid families by members of their own community. Inadequate outreach is reflected in the extremely low rates of participation in EPSDT. Currently, only about one-quarter of the screens needed by eligible children are provided. Unless provisions for effective outreach are included, as in the past, few of the eligible children in need of CHAP services will actually get them.

The Administration's proposal includes a higher federal match than is generally available for outreach services. But as the current program has shown, mere availability of federal funds does not lead States to institute effective outreach programs. While we support flexibility for States to design programs specific to their needs, we believe certain minimal guarantees are essential to achieve the program's purpose. Therefore in addition: States should be expected to earmark at least a certain portion of the program budget for outreach and; States which do not reach (i.e., assess) a reasonable proportion of eligible children who need assessments should be required to develop new outreach programs emphasizing the use of organizations located in the target community.

Developing States' Capacity to Deliver CHAP Services

Unlike other Medicaid services, CHAP charges States with putting in place many services and seeing that children receive them. This calls for a kind of planning and administrative capability different from other Medicaid provisions. CHAP does not adequately address these affirmative aspects of the program; nor does EPSDT as it is now administered.

To carry out an effective CHAP program, States must set out a strategy capable of meeting program goals, building a statewide system for delivering the services, and gaining broad-based cooperation from a range of personnel who work with children. Under EPSDT, there has been little and in some places no attention to these activities. Provisions should be added to strengthen State plan requirements. States should develop (with substantial public input) an annual State plan demonstrating the capacity to meet program requirements.

Health Services

CHAP seeks to make available to children preventive and primary health services. The Administration's CHAP proposal includes a significantly improved benefit package for Medicaid-eligible children. However, many children, particularly children with handicapping conditions, will still go without needed care because States can opt not to cover a range of health services (e.g. physical therapy, speech therapy, prosthetic devices, and some clinic services). In addition, States are allowed to place limitations on the amount, duration, or scope of routine dental services, and ambulatory mental health services provided by clinics (unless precluded by minimum service requirements set by the Secretary), and all optional Medicaid services.

The purpose of a primary care program is to prevent or treat early on children's health problems. For CHAP to identify a child's health needs but not provide the services to treat the problems defeats the purpose of the program. Furthermore, the services unavailable through CHAP cannot necessarily be gotten through

other programs. Other federally-funded programs reach only a small portion of the CHAP children who need their services. And, many of these programs are dependent on third-party reimbursement through Medicaid for financing.

Allowing limitations on the amount, duration, or scope of basic services is inconsistent with the goals of CHAP. First, one of EPSDT's most important departures from Medicaid was that it overrode State plan requirements in some treatment areas, including dental care, by calling for coverage of necessary treatment. CHAP is intended to build on this concept by expanding the scope of services to cover all needed care. Allowing limits in amount, duration, or scope undermines the receipt of necessary care and moves CHAP in some instances a step backwards. Second, in the case of mental health services and some clinic services, such limitations would be applied to services provided by organized care providers. These limitations will function as disincentives for health centers and clinics to participate in the program. Yet, these are the providers most likely to provide children ongoing health care and mental health services at the least cost.

Because the cost of adding these few services to the mandatory benefit package is modest, and because the need for a full range of primary health care services is great, CHAP should include at a minimum coverage of all needed ambulatory care for Medicaid-eligible children without limitations in the amount, duration, or scope of these services.

Dental Services

There is a wide consensus that children need routine dental care. Including coverage of routine and emergency dental care as a Medicaid benefit for children is an important improvement in the new CHAP proposal. Despite this expansion of benefits, however, Medicaid-eligible children will still go without needed dental services because of several serious deficiencies in CHAP.

The Administration's proposal requires States to inform all eligible children of the need for and availability of dental services. States must additionally refer children to dental providers on a timely and periodic basis. Under this scheme, there is no requirement that States make maximum use of qualified dental providers, or develop methods of reimbursement and administration which assure the statewide availability of dental providers. The Administration's proposal fails to assure the availability of resources to deliver covered services.

Furthermore, under CHAP, responsibility for referring children or following up on the referrals is misplaced or nonexistent. No agency or provider is responsible for follow-up to see that needed dental care is actually received. Responsibility for referrals is given to the State agency. To be most effective and efficient,

however, referral must be an integral part of the health assessment.

States should be required to assure the availability of dental providers, make maximum use of all qualified dental providers, and actively encourage participation of others by offering attractive administrative arrangements. CHAP should make direct referral to a dentist a provider responsibility and specify responsibility for follow-up on such referrals to assure that children are getting the care for which they were referred.

Maintenance of State Effort

The primary purpose behind increasing the federal share of CHAP expenditures is to encourage States to strengthen and expand their programs. Yet, a significant portion of CHAP's \$288 million federal budget will go to increased federal matching for CHAP services for children who are currently eligible. In order for the increased federal share to result in program improvement and expansion, States must maintain their current level of financial commitment. Otherwise, the new federal dollars will simply replace State funds and will not result in benefits for new children.

CHAP should require States to maintain their current level of State Medicaid expenditures (both total and per capita) for out-patient services for the under-21 population.

Federal Enforcement

While we support using incentives to get States to implement the CHAP program and provide primary care to children, when States do not meet standards HEW should have ways of accomplishing compliance with the law.

In the Administration's bill, enforcement is accomplished through the financing system. The "penalty" is a graduated adjustment of the Federal matching rate for ambulatory care to children no lower than five percentage points below a State's current federal matching rate.

The effectiveness of any compliance measure depends on the level of performance which triggers the enforcement mechanism and the impact of the penalty for not performing adequately. It is doubtful the Administration's approach will have sufficient impact to bring about compliance. In some States it will be cheaper to absorb the reduction than mount an adequate CHAP program. Second, since the reduction in the federal match is applied to expenditures for ambulatory care services to children which comprise a fraction of overall costs (as opposed to in-patient care, which makes up the bulk of state expenditures), it is less likely to have an impact on State performance. Third, since the reduction is applied to service-related funds, it is likely to be harmful to program beneficiaries.

CHAP should establish a minimum acceptable level of performance for purposes of determining whether a financial penalty should be applied. States not meeting this level should receive a substantial reduction in the federal share of Medicaid administrative costs.

Building Accountability in HEW's Administration of CHAP

The history of EPSDT has been characterized by foot dragging at the federal and state levels and a pronounced failure by HEW to provide the necessary support and leadership.^{1/} We are extremely hopeful that this Administration is committed to vigorous action to see that children receive the benefits to which CHAP entitles them. At the same time, we believe it important for the Congress to institute certain minimal forms of accountability. CHAP, as presently written, does not include such measures.

Had EPSDT included benchmarks against which the Congress could monitor the progress in providing children with needed care, EPSDT's poor performance would not have persisted these ten years. We believe it essential that they be established under CHAP. Therefore, we recommend as a target that 80% of eligible children be enrolled in the program within five years of enactment. In addition, an independent evaluation of HEW's administration of the program should be conducted and submitted to Congress on a biennial basis by an outside panel of experts representing the interests of recipients. Finally, in addition to the charge already in CHAP to review overall state performance on a biannual basis, HEW should be charged with monitoring state performance regarding provider participation and with reporting to Congress on provider participation in CHAP and the steps being taken to use all qualified providers in the program.

^{1/}See FPSDT: Does It Spell Health Care For Poor Children?
pp. 54-59.

Mr. MAGUIRE. Thank you, Ms. Weitz.

Mr. Dannemeyer.

Mr. MAGUIRE. I don't have any questions.

Mr. MAGUIRE. You mentioned in your statement the need for insuring that the provider will provide followup so that the child actually gets to the dentist after referral has been made. You make a particular point out of that in dentistry section, I believe.

Ms. WEITZ. What we had said was that referral to a dentist should be a provider responsibility and that the responsibility for doing the followup should be assigned; I don't believe we say that necessarily should be the provider's responsibility.

Mr. MAGUIRE. Then the first question would be, where should that assignment be made for responsibility for followup?

Ms. WEITZ. That is a very difficult question. From the point of view of what would work best for kids, planning it into the provider would keep some continuity. On the other hand, we are very realistic. Some providers just don't have the resources to do that kind of followup. Therefore, if the State agency was responsible for doing that followup, we could live with that.

Mr. MAGUIRE. If the State agency were made responsible?

Ms. WEITZ. Yes.

Ms. LAZARUS. The one model that might be considered here is the provision in your own bill, and in Dr. Carter's bill, which allows providers to do followup on any kind of treatment, whether it be dental or otherwise, or gives them the option, if they are not capable of doing this, of contracting with the State to do it. That may be a realistic approach.

Ms. WEITZ. If they are going to do followup on dental, or any other service, it is important to negotiate the costs of doing that in with the reimbursement rates for medical services.

Mr. MAGUIRE. Would you apply the same principle to eye doctors, speech therapists, nutritionists, et cetera.?

Ms. WEITZ. I am sorry, I don't understand you.

Mr. MAGUIRE. That referral followup responsibility assignment process.

Ms. WEITZ. Yes. We are not distinguishing between followup for dental and followup for other services.

Mr. MAGUIRE. We make a special point with respect to dentistry. I take it you want to extend that to all other.

Ms. WEITZ. It was the issue of followup for dental care that was not addressed in the appropriate manner in the administration's bill and that is why we talked about it exclusively.

Mr. MAGUIRE. But you do like my bill?

Ms. WEITZ. Yes, sir.

Mr. MAGUIRE. Good. There may be areas where you believe that my bill could be improved. Most of your comments have been addressed to the administration's bill. I wonder if you would have any comments on how our bill might be improved?

Ms. WEITZ. I think one of the things we particularly liked in the administration's bill is the fact that the benefit package is available to all medicaid children, not just those who have been assessed. So, I think that that is something that we hope maybe you can be persuaded to change in your bill.

Ms. LAZARUS. I have one additional point to make here. We are delighted to see the emphasis that your bill places on outreach and consider it the strongest of the bills in terms of outreach. Your bill includes a provision which would earmark a reasonable proportion of program funds for outreach and gives priority to community based organization. I think we would like to see one additional step: In the instance where States are using this special earmarked fund but are still not successful in bringing children into the program, they must start doing business with organizations that are actually situated in the target community.

Mr. MAGUIRE. If they are not meeting some standard at the moment.

What is your answer to the argument that noncommunity based organizations that belong in outreach would be discriminated against if they only got 75 percent whereas the community based groups got 90 percent?

Ms. LAZARUS. I think they would be a lot better off than they are now.

Mr. MAGUIRE. They would be better off.

Ms. LAZARUS. Noncommunity based groups which are now getting 50 percent would get 75 percent. So, they are faring far better and that is proper.

Mr. MAGUIRE. What would be your argument though in favor of a differential at that point?

Ms. WEITZ. I think our argument would be that most of the evidence, and that is quite a bit, about what constitutes effective outreach shows that when outreach is done by organizations based in the community by people known and trusted by the families it is most successful. Therefore, one should build incentives which are going to encourage those sorts of providers to do that outreach.

Mr. MAGUIRE. I hope I will be able to convince my colleagues.

Ms. WEITZ. I certainly do, too.

Mr. MAGUIRE. Everybody is always talking about fairness, you have to be fair to the community based groups and noncommunity based groups, give them the same treatment.

Ms. WEITZ. In that sense your bill is the fairest. After all, your bill is the only one that gives a 10-percent increase for inpatient services whereas the others give an increase only to ambulatory care services.

Mr. MAGUIRE. That is an interesting way to argue the bill. Good.

Ms. LAZARUS. I think the point is, too, that the financing for outreach that we support, and which is in your bill, is based on experience. There are grounds in this case for giving slightly increased higher match for outreach to these more effective organizations. At the same time, you are doing very well by and in fact bettering a lot of noncommunity based organizations.

Mr. MAGUIRE. Then somebody is sure to pop up and say, "But some of these organizations are just going to pocket the money," and what have you. What is the answer to that?

Ms. LAZARUS. We believe that there is a way to build in an increased Federal match to these organizations up to a particular point. According to our calculations, we think that if you pay 90 percent Federal reimbursement, up to \$6 per child enrolled, that that is the reasonable way to control an effective outreach and

prevent pocketing of funds. There are indeed workable ways around that.

Mr. MAGUIRE. What did you think of the administration's presentation of their continuing care category? What comments would you have on that? Is that something which we should be doing to separate out this group with written agreements for continuing care and leaving everybody else, if I may say so, in the lurch or is this a good idea that we ought to build on top of what we propose in my bill?

Ms. WEITZ. We would like to set out the responsibilities a provider must meet and have any provider who can meet those responsibilities be allowed to participate in the program.

Mr. MAGUIRE. So you would have one standard then rather than two categories.

Ms. WEITZ. What the Department is trying to do is to build in incentives for using those providers which can provide a range of services to children so that the kids don't fall between the cracks. I am not sure they have really built in the incentives to attract those sorts of providers into the program. That is what I am most concerned about.

Mr. MAGUIRE. They have a 1, 2 factor for reimbursement.

Ms. WEITZ. That is true. But, that higher reimbursement goes to the State. It does not go to the provider. To the degree that puts the heat on the State to recruit comprehensive care providers because it is to the State's advantage it works. But, that does not necessarily mean that the health care center will get more money.

Mr. MAGUIRE. I didn't fully understand that. How would you structure something that would get to the provider?

Ms. WEITZ. Well, there is a provision in the bill which says the Secretary may set a minimum fee schedule or establish per capita rates. I think the "may" should be changed to "shall."

Mr. MAGUIRE. "Shall" does not always happen.

Ms. WEITZ. That is true.

Ms. LAZARUS. We support the very important provisions which are in yours and Dr. Carter's bill which would give the States the responsibility of setting up terms for providers which would reasonably elicit their participation in the program. This gets at levels of reimbursement and the promptness of payment.

Mr. MAGUIRE. My concern is we come back in 3 years from now and look at this thing and say, gee, why didn't we figure out some way really to encourage people to participate and for cases to be managed on individual children over the time that we would want and so on, and there are 50 reasons why we didn't quite do it retroactively. Providers are not going to be sufficiently encouraged. Some case management is going to improve but mostly it won't because all we do is fall back on the State agency to be in charge of case management and there is not anybody right there close by that really can be assigned that responsibility and so on. Suddenly we find ourselves even with these improvements in very much the same situation.

Ms. LAZARUS. It is true though that between hearings this year and last year there has been considerable airing of those issues. There has been quite a lot of experience in the program itself to

date and the ingredients for some of the best solutions are out there amongst the three bills.

Mr. MAGUIRE. We are not going to be able to get everybody to agree to the provisions and then we will just be that much further behind.

Go ahead.

Ms. LAZARUS. I think it will be very important to hear from a range of providers as to what features of the three bills most meet their needs because that ought to be quite a high priority.

Mr. MAGUIRE. OK. Do either of you have any additional comment on the rather lengthy discussion we had this morning, points that struck you as being ones that you would like to comment on?

Ms. LAZARUS. I think the one point that I would like to speak to was the question raised by the Congressman from California. How is it in this day when everybody is complaining about the budget difficulties that we can justify a program of this size? I think the single most important point to simply get in the record here is that it is a question of paying something now or paying quite a bit more later. We have supplied on other occasions testimony on the very concrete cost savings that accrue from spending money on preventive care for kids now and while it is an investment which is not insignificant I think it is terribly important that the full Congress understand the cost of not enacting this legislation now.

Mr. MAGUIRE. I emphatically agree with that which is why I pressed for funds beyond those that the administration indicate a willingness to provide.

I would like to ask one question on behalf of Dr. Carter if I may. Some say we should hold passage of CHAP until we have reformed title V programs. Would you agree; why or why not?

Ms. WEITZ. No, we don't agree. The title V program is a very important one and one that we should take a hard look at. In fact, we are in the process of doing our home work on that and it is not at all clear to us yet what needs to be done with the program, what the solutions are, and whether they are legislative solutions that are needed. We have had a tremendous amount of discussion and many reports on EPSDT. We are ready to move and people know what needs to be done. Let's not hold up doing this modest but important thing for kids any longer but move ahead and accomplish what we can now.

Nothing in CHAP precludes moving on title V at a later date or makes it any more complicated. I would hate to see us lose this opportunity and let another session of Congress go by.

Mr. MAGUIRE. Thank you. We will resume shortly. There is a vote on the floor.

The next witness will be Dr. Birt Harvey.

We will be back in a moment.

[Brief recess.]

Mr. MAGUIRE. The subcommittee will come to order.

Our next witness is Dr. Birt Harvey, a pediatrician. Dr. Harvey is representing the American Academy of Pediatrics.

STATEMENT OF BIRT HARVEY, M.D., ON BEHALF OF AMERICAN
ACADEMY OF PEDIATRICS

Dr. HARVEY. Thank you, Mr. Maguire, for the opportunity to testify on behalf of the academy.

We have, as you know, had a long interest in EPSDT and associated matters. We support the concepts of the three CHAP bills in that they give better coverage, and they cover more children. We are also heartily in support of the concept of preventive care for children to discover defects early and to place children in comprehensive health care settings.

Before addressing the specifics of this bill I would like to say that we feel it is important to coordinate child health care needs. Looking at title XIX needs such as CHAP in isolation and away from title V is inappropriate, unfortunately, title V expertise is not available in the title XIX programs, and for these programs to be administered effectively in the States it would be advantageous if the two programs were better coordinated.

Mr. Heim this morning stated there will be computers in all the States and this would simplify the problems of EPSDT data collection and followup, but the computers really don't differentiate when a child is noted as having an abnormality or a disease if that disease is a diaper rash or a heart defect. You do need the expertise of medical people involved in the integration of the two programs.

The title V people really are the ones who can best do case management. Title XIX people are not trained in this area.

We hope that there will be a new title V bill and that these two bills can be considered together. Basically we would like to see all child health care programs in the Federal Government integrated and coordinated in a much better way than they are, and this would lead to better coordination on a State level as the followthrough always seems to go. Now, there are too many agencies involved. It is just a myriad of child health programs which leads to gaps in programs, duplication and inefficiency. It is financially inefficient as well as medically, and there is minimal coordination. We would like to see a centralized responsibility for child health care programs administered at a high level within the Department of Health.

Let me make some comments about these three bills in particular. We are all for improved health, that is the chief goal of these programs. We feel that preventive care and picking up defects early is the way to go and that continuing care is obviously stated as one of the intents of this bill. The value of continuing care is obviously to prevent significant diseases from occurring, to give a less costly child health care and to make a less costly system operate.

When you give preventive care, you avoid hospitalization very often, you avoid emergency room visits. The family knows where to go. They don't go to the emergency room, they go early enough so that the defects are discovered before they become catastrophic and the child has to be hospitalized. It also avoids duplication of services by having a child in the medical home which gives continuing care.

Without a continuing care provider, very often poor children receive immunizations and nobody knows what immunizations they receive so they get duplicates of some types of vaccines and none of other kinds. They also get repeated workup for the same disease entity or the parents are not sophisticated enough to know anemia and the same workup is done again. It is both unfair to the child and costly.

There is also a better followup of the child in the continuing care setup if he comes back in and I see his records. I don't know whether this is ignored or not if he goes to a different place each time. There is no followup.

We approve of the administration's idea of financial incentives to States to get children into continuing care and we think the system of a 20-percent bonus to the States is a fine one. It does not necessarily have to be 20 percent but some system to stimulate States to get children into preventive care is good medicine and it is good financially.

One of our big problems with all three bills is the problem of the definition of the continuing care provider. They are listed in these bills by the title or by the location and they are not listed by what they do, what they perform by the function.

Dr. Davis this morning when she was asked what a continuing care provider was, identified a continuing care provider not by the definitions in the administration bill but by defining what a continuing care physician or clinic performs in the way of services, and we believe this is the best way to define continuing care. There may be private providers who can give good continuing care, and there may be schools that can also do it. Conversely, there may be providers or schools that cannot provide continuing care. We believe you ought to change the definition of continuing care and define it by a series of functions that a continuing care provider can perform as we outlined in our statement.

These are things such as maintaining records, having 24-hour availability to care or advise, providing care for sickness, providing checkups and a whole series of other things we mentioned. If these are listed as the parameters of who can provide continuing care, then you will really get true continuing care, but to identify a school or other location as giving care, that is not a proper way to define who gives continuing care.

There are several problems with the bills as we see them that are barriers to inducing private providers to participate in this program and would tend to end up resulting in Government agencies providing care for children. The biggest barrier is the written agreement. Most private providers do not sign written agreements that insure that followup will be done when a child is referred someplace else. When I as a pediatrician see a child, I give the parents the name and address and phone number of whom I want the child referred to if he needs followup, and I then let it go at that. I expect the family to follow through.

Now you can ask private providers to do more, but there are limits as to how much. They are not oriented to following through to see that a referral is completed, and if he does not get there to contact the family and if the family has no phone, to try to figure out how to send somebody there. In the same way, asking the

providers to assure that the child return for periodic checkups as is done in the written agreement will be a further deterrent to getting nongovernmental providers in this program.

Government agencies are the ones which have generally assumed these roles, the public health departments are the ones that have done this. To ask a nongovernmental provider to assume this role will require that he hire new personnel and develop a new orientation within his office. It is very different from the present system if you ask him to do followup things for dental care or followup to see other kinds of care. It becomes even more of a barrier.

We believe that it really should be the State's responsibility to do these and the State should be able to contract with providers who want to assume this role. Now if the provider is operating on the basis of capitation, then he may very well want to do this. He may agree, if he is contracting on capitation basis, to hire other personnel to do these kinds of specific things. None of these bills address funding for increased cost for capitation which would include such things as insurance of followup and assurance of returning for visits at periodic intervals.

One other item I would like to address is the accountability of States. We are very concerned that there be stringent requirements to show that the States attempt to meet the needs and the goals of this bill and not try and circumvent it. It is all too easy for the States to circumvent several intents of this bill. Getting children into an ongoing medical system, providing complete examinations rather than screens and to get them into followup.

We think the bill has appropriate goals in preventive care and in outreach, followup and in placing children in available sources of continuing health care. We think that the State should have to show the goals they are trying to achieve as well as numbers. They should have to outline the specific means they are using to achieve those goals and they ought to have an annual plan stating what percent of each numerical goal they are trying to achieve and how successful they are in getting there.

So if you took one of the goals of getting children into a medical home, then the State should show what they are doing each year to try and get children into ongoing systems of health care. They should have to show what they are trying to do to develop ongoing systems of health care in areas that do not have it so they don't automatically continue using screening indefinitely.

They should be required to demonstrate the degree of provider input and expertise. They should eliminate barriers to physicians' participating. We really need to be sure that the whole program is not made a screening program.

The last point I want to mention is data collection. The kind of data that is collected now gives you no useful information. The EPSDT data doesn't let you know any more where you are now than you did 7 years ago as to how effective a program can be. You know it is not effective but you don't know why, you don't know the problems, you don't know what works with outreach, what does not work with outreach. You don't know what is being followed up, whether the whole program is cost effective or not, whether certain segments are effective and certain other segments should be discarded. There should be good data collection and there need to be

understudies by outside sources who can evaluate. We would hope that there would be funds provided to have research groups evaluate and do studies on aspects of the program and that the Federal Government would provide funds enough to see that there is appropriate data collection in the States.

Thank you.

[Testimony resumes on p. 145.]

[Dr. Harvey's prepared statement and attachment follow:]

STATEMENT OF BIRT HARVEY, M.D., ON BEHALF OF AMERICAN ACADEMY OF PEDIATRICS

Mr. Chairman, I am Birt Harvey, M.D., a practicing pediatrician from Palo Alto, California, here today representing the American Academy of Pediatrics. The Academy is an international medical association and children's advocate representing 20,000 physicians dedicated to the care of infants, children and adolescents.

The American Academy of Pediatrics supports the basic concepts embodied in H.R. 2159, H.R. 2461, and H.R. 4053--that all children in this country deserve the opportunity to have preventive medical care, that defects and diseases should be discovered early, and that remediation should occur promptly. We believe that all children deserve an ongoing source of medical care. We have testified in the past in support of these ideals, most recently at the oversight hearings before your Committee on child health programs. Our chief concerns have been that the ramifications and problems associated with past legislation were not thoroughly studied before passage. This has resulted in a failure of EPSDT to properly function. Inadequate and ineffective past administration has only further compounded a floundering program. We have noted the recent efforts on the part of the Department of Health, Education and Welfare to improve the administration of EPSDT, and we will continue to work with them in an effort to resurrect the program. But we do believe that marked changes are necessary in several areas of the proposed legislation to avoid compounding several existing problems and to avoid creating another set of difficulties.

Federal Child Health Activities

Before entering into a discussion of specifics that need attention in these bills, we would like to point out that CHAP needs to be considered in broader context. CHAP will focus solely on children meeting eligibility requirements and cannot be seen as a health program for all children in a community. In fact, this is only one of the myriad of federal programs directed toward improvement of the health of this nation's children. A primary problem shared by this myriad of federal programs is the fragmentation of effort with resultant gaps and inefficiency. As such they are representative of incompletely developed approaches to meet the health needs of mothers, children and adolescents. The effect is that they promise far more than they can deliver or they act as divisive efforts in a community by competing for inadequate manpower and facility resources.

Your attention is directed specifically to the Maternal and Child Health programs under Title V of the Social Security Act--the dominant legislative expression of this country's commitment to health care for the maternal and child population over the past four decades. For the Congress to address revisions in Title XIX separate and apart from Title V would result in a failure of this Congress to fully utilize resources at hand to provide complete care to as many children as possible. The Title V program also needs to be refocused legislatively and its purpose redefined to develop both a generic approach to health care for maternal and child populations and a capacity to respond with special, focused

efforts to insure a coordinated, comprehensive program for all mothers and children. Such a proposal was introduced in the Congress last year (H.R. 10704) by Mr. Rogers and Dr. Carter and we would urge that it be considered by the 96th Congress. This proposal has been supported by the American College of Obstetricians and Gynecologists and the American Medical Association.

By focusing on both Title V and Title XIX, the intent of Section 11 of H.R. 2159 and H.R. 2461 can be fully realized. We would point out that the potential benefits to be derived from better cooperation between Title V and the CHAP program include: "...promotion of continuity of care, sharing of scarce expertise, avoidance of unnecessary duplication, efficient allocation of financial resources, and achievement of greater accountability. In short, more effective utilization of existing resources and development of more extensive health care resources." (Operational Guidelines for Interagency Agreements, proceedings of the National Conference on EPSDT and Title V Programs, January, 1977, p. viii.)

As stated in our testimony before this Committee on May 16, it would improve the efficiency, lower governmental costs, and better serve the health needs of children and adolescents were all programs administered by one agency. We believe that the Department of Health, Education and Welfare should centralize responsibility and authority for all child health programs at a high administrative level. Competent staff at both central and regional offices capable of developing and implementing coordinated approaches to the delivery of authorized programs need to be developed.

Eligibility

The Academy is supportive of the improvements in eligibility and financing that this legislation will bring. The inclusion of women who are pregnant for the first time who would otherwise not be eligible until after delivery will result in improved prenatal care and, consequently, healthier newborns. Infants who may realistically have problems with young, unmarried adolescents for mothers are less likely to have the further disadvantages of ill health, small size, congenital anomalies or many other problems. Including such women applies the CHAP resources in a truly preventive manner.

We are further pleased to note requirements states must reach on the amount, duration and scope of services in order to be eligible for federal matching assistance. This expansion of eligibility for CHAP services should help provide more complete preventive care to a significant segment of underserved and nonserved children. Provisions for coverage for children of migrants and incarcerated children are important provisions of H.R. 2159 and H.R. 2461 not included in the Administration's bill and we would urge they be maintained.

Proposed changes in this section should include mandatory rather than optional coverage in the 18-21 age group. Since Title XIX covers this group, it would be wrong to deny them services merely because the state

has decided not to include them. The continuation of coverage for six months after the loss of eligibility as in the Maguire-Waxman bill is preferable to the four months in the Administration bill. The process of diagnosis and treatment after examination is completed may frequently require six months. The bill might be more appropriately amended to require coverage until diagnosis and treatment are completed should a child become ineligible after screening or examination is performed. Alternatively, the state plan could be required to establish an administrative arrangement between the Title XIX and Title V agencies to assure continuance of care for children declared financially ineligible.

Provider Participation

We applaud the stated purposes of the proposed legislation, namely to introduce children into a continuing comprehensive health care system within their community. Giving a child a "medical home" provides the family with a feeling of security and support when medical need arises. Families with a medical home or personal physician are less likely to delay seeking care, hence illness can be treated earlier, before it becomes catastrophic. Subsequently, families gain confidence in the source of their care and are more inclined to seek preventive care. Thus an ongoing source of health care for each child avoids unnecessary duplication, fragmentation, episodic and incomplete care, as well as being less costly and more humanitarian, and immeasurably improves the health status of children. Unfortunately, language in all bills fails to effectively implement their stated purpose. To give as many children as possible a "medical home" requires the utilization of all types of comprehensive, continuing care providers. The private sector has under EPSDT been systematically excluded from participation in 22 states, and certain sections of these bills will erect a further barrier to this large segment of continuing care providers. Section 4(n)(3) of the Maguire-Waxman bill and Section 1913 of the Administration bill require written agreements with providers in which they insure that follow-up service is received on a timely basis and assure that child health assessments are performed on a timely basis. Those physicians in private practice may not have the properly trained personnel to perform the tasks set forth under the "written agreements." These responsibilities have been left in most instances to the families and in certain circumstances to the county and city health departments with appropriate expertise and experience. This is not to say that case management is not important, but that accountability should lie with governmental agencies unless the provider has the ability and desire to assume this function. Physicians assume responsibility to provide care but cannot under ordinary circumstances assume the responsibility to see that the family utilizes available services. While such requirements with written agreements may be appropriate for private providers who contract for care on a capitation basis, details of how resources will be made available to finance and support such services are not addressed in either bill.

Our greatest concern lies with the definition of health care provider as outlined in Section 4(n)(4) of the Maguire-Waxman bill and Section 1913(e)(1) of the Administration bill. As defined, these providers are

to deliver continuing, comprehensive ongoing care for children. The identification of who can provide such care cannot be made categorically, simply by listing types of providers. Rather a listing of specific requirements for any individual or group who may wish to qualify must be developed. At the request of the Administrator of the Health Care Financing Administration, the Academy has prepared a definition of a comprehensive continuing care provider (see Appendix I). There will be private practitioners, day care centers or others listed who do not qualify. Conversely, there may be groups not listed who can well provide such care. The important criteria are not the setting or the title of the group, but the services it can offer to meet the needs of children. We would suggest the following amendment to this section:

The term "comprehensive continuing health care provider" applies to an individual or group who provides: 1) initial and periodic health examinations, 2) treats conditions amenable to treatment, if possible, or refers for appropriate care, 3) accepts continuing responsibility for providing care to maintain physical, mental and social health, 4) coordinates all medical services the child receives and interprets the processes and findings to the child and/or family, 5) maintains and has available whenever needed, health records of the child, 6) provides anticipatory guidance and health education for the child and/or family, 7) provides day and night, weekday and weekend availability for advice and access to care of acute and emergent problems.

The bills at present--stipulating written arrangements for insurance of follow-through and assurance of appearance for periodic examination and listing of qualified comprehensive continuing health care providers by category only--will foster institutionalized arrangements for the provision of care to poor children by mediating against involvement by non-governmental providers. This will promote government run clinics as the sole mechanism to provide health care to the poor; it runs counter to the concept of a pluralistic system of health care involving a multiplicity of provider resources and freedom of choice for the consumer to choose a provider of care. The reality is that all providers must be involved to accomplish the task.

While it is our desire, as it is yours, to help all children find a source of comprehensive continuing health care, we realize that it is unrealistic to believe this can be accomplished at this time. There are many pockets in this country, both rural and urban, where the supply of comprehensive continuing health care providers is not equal to the demand. However, this should not offer states an excuse to funnel as many children as possible into screening clinics, nor to set inadequate standards for such clinics. The Administration must not rely on numbers of screens as an indication of success when such screens often pay only lip service to the objectives of this program while not effectively even really screening the children. Thus there need to be criteria for assessment providers just as we have recommended for criteria for

comprehensive continuing health care providers. These criteria should include competency of staff, standards of necessary equipment, a reasonably fail-safe plan to refer children to an appropriate comprehensive health care provider for a needed diagnosis and treatment in situations beyond the capacity of the screening provider, and a sensitivity to the emotional needs of the families of the children screened.

Claims Forms

At present the reporting and billing forms vary in content and complexity from state to state. The lack of equivalence between states with regard to records and paperwork impedes the continuity of care. We support the Administration's efforts to develop a uniform reporting system and a uniform claims form. These could prove advantageous in simplifying the system and thus improving provider involvement.

Minimum Reimbursement

The inadequate fee structure in many states has been the deterrent in participation by many provider groups. We approve in principle the Administration's plan to develop a basic, minimal, national fee structure but believe it must be flexible and based on regional and state differences. We would like to see fees negotiated separately in each state but with a floor established by the Secretary at a level that would permit participation of comprehensive continuing health care providers.

Penalty Provision

The development of financial incentives to stimulate involvement of more poor children in screening and in comprehensive continuing health care is an excellent idea. For too long the mentality of the program has been punitive. Rather than attempting to help states develop viable, effective programs, the primary involvement was to see if penalties were in order. As a consequence, the attitude of most states has been directed toward avoiding penalties rather than toward serving the health needs of children. It has become a numbers game rather than a health improvement game.

State Accountability

The Academy approves the objective of state accountability for an effectively functioning program as outlined in H.R. 2461. Requiring state plans to inform and attract all eligible families in a timely manner to facilitate obtaining comprehensive or screening examinations and to see that necessary follow-up is achieved is an important objective. The Administration's proposal to provide incentives to involve children in a continuing care system are excellent. States should be required to report on methods and techniques used to achieve this objective. They should be required to disclose methods used for facilitating involvement of all potential local health care resources for the program and to show cause if there is no private provider participation. A description of state provider outreach, adequacy of fee structure and mechanism of provider input into the program should be included. Since a major objective of the program is to have all children enter a continuing health care system, it is the responsibility of the state to justify the

use of assessment providers. Such an approach should be used only when comprehensive continuing health care providers are unavailable.

The intent of Congress to see that all children should eventually have a permanent medical home needs to be clearly spelled out so that states will not stop at putting children through screens but will be compelled to find medical homes for all children in this program. We must recognize that assessments represent a temporary and inferior health care, and that each state which finds it necessary at this time to have some eligible children served only by assessment providers, should submit as part of the state plan steps and timetables to move aggressively to have all children in continuing comprehensive care settings. If it is not made clear that assessment is a temporary expedient, we will find some using assessment providers almost exclusively. States should be required to set outcome standards and goals in their state plans and should further be required to report their progress in relation to their goals. What we seek from the state in such a requirement is a data base providing not only gross numbers of children examined and treated, but an accounting of what happened to those children in the program's system. By the same token, goals and progress reports covering practitioner participation should be required each year.

Since the essence of the program is adequate follow-up to achieve remediation of potential defects or diseases discovered in the examination, state or provider efforts to see that successful follow-up is achieved emerge as the critical facets of the program. That success cannot be assessed in numbers alone but requires a detailed reporting system, so that the true effort expended to help these children can be determined. We do not believe that either bill is presently written to achieve the objective of making the states truly accountable and effectively evaluating their efforts to improve the health of eligible children or facilitating their entrance into a continuing care system. Thus, in Section 7(c)(1) of the Maguire-Waxman bill, the states are asked to list the proportion of families informed in a timely manner. This should be expanded to require states to disclose methods used for informing, what plans are being developed to expand the percentage being informed, and what their annual goals are. In item (ii) of that section, states should be required to report on the number of children examined by comprehensive continuing care providers as an indicator of entry into a system of continuing care. They should be required to show plans for increasing the numbers assessed and the numbers entering continuing care and to show what efforts they are making to implement these plans. The numbers and percentages of different types of comprehensive care providers involved in each state should be reported. States should also be required to show what plans they have developed and what efforts they are making to increase the involvement of a variety of different comprehensive, continuing care providers. Annual goals for increased provider participation should be required. Section (3) should require states to report not only the provision of medical care for diagnosis and therapy, but what techniques are used to obtain this care--how adequate it is, what plans are being made to expand availability of such care and what efforts are being made to implement these plans. We note that the Maguire-Waxman bill, in contrast to the Administration's bill,

has provisions requiring the Secretary to report to Congress annually on the performance of the program. We believe this to be of utmost importance, particularly in view of the sorry state of this program after so many years. Recent, renewed interest in the program by the Health Care Financing Administration is to be commended, but is no substitute for ongoing congressional surveillance and requirements for accountability for successful implementation on the part of the Secretary. Such a report should contain data on cost effectiveness, analysis of the program's components, assessment of the program goal attainment, and clarification of the problems inherent to the program. The requirement should allow changes to improve the program, eliminate problems, and pave the way for future child health legislation.

Evaluation and Research

These bills do not give appropriate attention to the collection of meaningful data on the CHAP program. The number of children screened and the number of examinations performed tells us nothing of the value of the program. Similarly, the number of defects found, referrals made or treatments completed are meaningless. The defects might be as insignificant as a birth mark or as catastrophic as a congenital heart defect. The disease might be as unimportant as diaper rash or as significant as leukemia. Funds must be provided to accumulate meaningful data on the impact of CHAP on the health of children. Without those funds, we will not know if the entire program is cost-effective or if certain aspects are particularly beneficial or particularly valueless. We would not be able to identify the most appropriate expenditure of funds, where more should be allotted and where less.

After all the time EPSDT has been in place, we are at a loss to determine what, if any, value it has. This should not be the fate of CHAP. When another Congress decides further revisions are in order in five or 10 years, it should not be faced with the same problems of attempting to evaluate an ongoing program and authorizing significant changes without adequate information.

We would urge the allocation of some percentage of the funds for formal, ongoing evaluation of CHAP. Data gathering, system development and analysis should be federally funded programs in a manner similar to ongoing research in this important program. The research requires sound scientific conceptualization and methodology which can be clearly set forth in formal field research applications through the data evaluation and research arm of CHAP.

American Academy of Pediatrics

Comprehensive Care Provider/Personal Physician

A Comprehensive Care Provider/Personal Physician can be defined by the following eleven points:

1. Provides initial and periodic health assessment services which include: a) a complete history which encompasses prenatal, birth and perinatal history, growth and developmental history, dietary history, family and genetic history, history of past illnesses, injuries and hospitalizations, review of identified allergies and symptoms by organ system, immunization history, family history of disease, medically relevant social history, names of other current providers of care, summary or records of current chronic disease conditions, identity of medications or treatments currently used, history of any present illness; b) a medical evaluation (including an unclothed physical examination) which assesses: general physical status, growth and development, including learning, vision and hearing status, status of mental and social health; c) screening and diagnostic tests appropriate for age and population groups; d) immunizations appropriate for age and health history.
2. Treats conditions that are amenable to therapy and to the extent that they are within his capability, otherwise, refers to another provider who is able to provide appropriate treatment services.
3. Accepts continuing or longitudinal responsibility for the whole child in health and in disease, and provides constantly available access to care and continuing guidance regarding acute and chronic problems of physical, mental and social health (see 11).
4. Coordinates medical services which are provided by others, interprets medical care processes and findings to the child and his or her parents, assists parents in communicating about the child's health status and needs to other physicians, schools and community agencies, and guides the parents in continuing supervision of the child's health.
5. Maintains records of the findings, corrective measures, and other health services received by the child.
6. Provides anticipatory guidance and health education services appropriate to the child's developmental status, acute and chronic health problems, and family social condition.
7. Educates the family as to the benefits of preventive care and informs them and assists them in scheduling preventive services of appropriate type and time.

8. Cooperates with the Medicaid program, or other designated agency, with appropriate previously obtained parental permission, if particular children have missed several appointments and are not able to be contacted.
9. Submits reasonable reports, previously agreed upon, and without violating the confidentiality of physician-patient contract, as required by the state.
10. Continuing medical care of children is provided by physicians whose interest, training and experience appropriately prepare them to provide a broad spectrum of health services to infants, children and youth, and by nurses, physician extenders, and allied health personnel appropriately prepared and working under supervision of such physicians.
11. Provides 24-hour, 7 day per week, availability for advice and access to care of acute and emergent problems.

Where comprehensive care providers/personal physicians meeting the above definitions are not available in a given service area, the Medicaid program should identify disincentives which prevent providers from locating in that area, propose and develop incentives which will correct such deficiencies, and utilize providers having lesser qualifications only on a temporary basis until comprehensive providers/personal physicians are available.

Outreach. All Medicaid agencies should directly, or by contract with other agencies or providers, provide outreach services to all families of Medicaid-eligible children. These outreach services should include:

Information regarding recommended preventive, acute and child health care services.

Assistance in obtaining medical history and records.

Assistance in arranging appointments and follow-up on missed appointments.

Transportation assistance when needed.

Arrangements for care of other children when needed.

The Medicaid agency, as a part of its outreach effort, should also cooperate with comprehensive care providers/personal physicians in assuring that there is availability in each community of services for family counseling, nutritional guidance, and child developmental education.

Mr. MAGUIRE. Thank you very much for your helpful statement. Now the American Academy of Pediatrics has taken a position in favor of CHAP legislation.

Dr. HARVEY. That is right.

Mr. MAGUIRE. So the suggestions you are making are, if you will, suggestions for fine tuning of an approach which generally you support.

Dr. HARVEY. That is right.

Mr. MAGUIRE. Now you mentioned the barriers to participation by private practitioners and I believe you said in your oral comments that the written agreement was the biggest barrier.

Dr. HARVEY. One of the biggest barriers, yes.

Mr. MAGUIRE. One of the biggest barriers. Would you propose that there not be such an agreement?

Dr. HARVEY. I think there can be. If it is a fee for service, there does not need to be agreement. There is in many States no agreement now when it is fee for service. When a provider signs a form and sends it into the State to collect his fee and to show what has been done, his signing of that form is essentially saying, "I have performed the services that have been requested by the State." Most private providers when you see a patient in your office, you don't sign an agreement. As soon as you start written agreements, there is going to be an awful lot of providers who say, "I don't want anything to do with that, that is not my style and I have not been involved in that."

Mr. MAGUIRE. But on the other hand you are saying you don't think you can list by category providers who would qualify by their very intrinsic nature as continuing care providers and you suggest instead that there be a description and you have even offered amendatory language to specify what the description should include of the services that they would be prepared to provide. How do you close on that kind of a set of conditions without some sort of a written understanding?

Dr. HARVEY. Well, what we have in California is a list of things in the statute which is required by anybody who sees a child under our CHAP program. When I fill out a form and check that the child had a physical examination, his hearing was checked and so on, and when I sign that form at the bottom right above it it says, "By signing this form you agree that you have met all the regulations of this program."

Mr. MAGUIRE. Well, do you think that most pediatricians would record themselves as continuing care providers in the sense that you have described a continuing care provider?

Dr. HARVEY. Yes. I think most of them would.

Mr. MAGUIRE. Would you say that there is substantial support for CHAP among the great bulk of pediatricians not just in theory but in terms of their willingness to participate along the lines that you have described, which would be essential for continuing care?

Dr. HARVEY. Provided all the other problems that have gone on EPSDT also are dealt with and they have been mentioned before. The inadequacies of the fee structure, the complexity of the forms, the slow turn around time in payments—all these things have to be dealt with. In other words, if there is no written agreement, that won't get people to get involved any more than they are now

if the fee structure is so inadequate that it barely meets the overhead expenses.

Mr. MAGUIRE. We heard the reimbursement incentives would go to States rather than practitioners under the administration proposal. What do you think about that? Should it be a way of getting some of those incentives to the practitioner?

Dr. HARVEY. I think that is up to the State. The State should be accountable to show what they are doing to get all types of providers involved, including private providers. Now if they want to put some kind of bonus for somebody who provides ongoing care, that might be a system that would be up to the State but the State would have to make efforts to see that it had all kinds of providers involved in providing care to the children.

Mr. MAGUIRE. Are there any other main barriers that you have not yet mentioned to participation aside from the written agreement, the redtape, the administrative problems and so on?

Dr. HARVEY. I think these are the chief barriers. There may be others that I am not thinking of offhand but these are far and away the main barriers.

Mr. MAGUIRE. You said the States would be best able to do case management. Now why would that be the case if the primary provider who knows the family and the child and so on is right there on the spot, if you will, maybe even with some help from paraprofessionals or others?

Dr. HARVEY. I am sorry.

Mr. MAGUIRE. Could provide followup and case management. Why would you not want that to be included in the things that continuing care providers would provide?

Dr. HARVEY. Well, under ordinary circumstances if you see a child and refer him for further care, you expect that person to go ahead and get the care. If he does not get the care, it is very difficult for the physicians to see that he does. The way offices are structured most providers don't have social workers, or other workers who are involved in this kind of outreach of going and checking why the family didn't get to the person they were referred to. Many people who are eligible for CHAP don't have phones and you try to contact them when you don't hear that they have gotten to referral sources and you have no way of doing it.

Now the counties are set up with public health nurses who can go and do this kind of service, they are oriented toward it. Now some providers may very well feel, OK, I will go ahead and hire, I will arrange and teach some people to follow through this way but that would have to be on a capitation contract kind of basis because it is not part of the usual system and structure of the delivery of private care in this country.

Mr. MAGUIRE. OK. What about subcontracting to local organizations, even community based organizations? Would that be a possible methodology if we are trying to develop new strategies for reaching, let's say, lower income people that might not have phones?

Dr. HARVEY. I think that might very well be an effective way. The only problem is that if the initial approach to the provider is one of the provider signing a written agreement, you agree, you assure that the person will get to follow up. If the provider doesn't

want to do that, maybe the State agency will make a contract with the provider to see that we do it. That may very well be a barrier while if it were done in terms of the State or agency will take care of these patients and will follow up but if the provider wants to assume followup role, he may, it is a much more positive way of involving more providers. It is just which way you look at it from which side.

Mr. MAGUIRE. I have to literally run over to vote now and I am going to leave Karen Nelson here to ask a couple of additional questions.

Dr. HARVEY. Thank you very much.

Can I add one other thing from earlier when we were discussing whether pediatricians would participate. We have done a manpower survey of all members of the academy in this country and one of the questions that was asked was, "Would you take care of medic-aid children?" Eighty-five percent said yes. All right. Now that obviously means that the situation has to be one in which they feel comfortable taking care of medicaid children and not one in which they feel there are a myriad of problems that are a deterrent right at the start.

Ms. NELSON. Did you also ask them if they were taking care of medicaid children at that point?

Dr. HARVEY. Yes, and a very high percentage—66 percent.

Ms. NELSON. The other issue that Congressman Maguire wanted me to address on his behalf is this: There is a difference in the bills before the committee in terms of the extension of eligibility beyond the point where because of the change in family income the child might otherwise be ineligible to receive medicaid services. Several of the bills suggest a 4-month extension, others suggest a 6-month extension. You have indicated, I believe, that both of those are inadequate. Can you tell us a little bit about how long a time frame you think there needs to be, and what conditions would take longer to treat than that?

Dr. HARVEY. Well, it can be a long time from screening through diagnosis and starting treatment. In many poor families it may take quite a while. How long it may take to complete treatment is a variable thing depending on what the illness is. To limit it to 4 months or 6 months as appropriate may be true in many cases but there may be somewhere it is not.

So however it is done we think you ought to consider having a proviso that if diagnosis and treatment are not completed, whether it is 4 or 6 months, there will be an extension granted for completion of treatment up to some finite time, whether it is 1 year or 2 years, or that there be arrangements made if it is appropriate that the title V programs in the State pick up that child's care. In other words, if it is a child with a congenital heart defect it could be turned over to the crippled children's services.

Ms. NELSON. Let me ask one last thing. The administration gave us this morning their tentative definition of what would constitute continuing care. I know you have been working with them, but I would appreciate it if you would take a look specifically at that and let us have your comments as to where you think that needs to be changed, and what is appropriate.

Dr. HARVEY. In the written testimony, I left a list of about eight items that we think are what really constitutes continuing care. In the back there is an appendix which is much more elaborate but we broke it down on review into about six or eight items, which are listed in the written testimony. Is that satisfactory or do you want any further elaboration.

Ms. NELSON. It parallels very closely what the administration gave us.

Dr. HARVEY. It does. I realize that.

Ms. NELSON. We already had the previous witnesses give us opinion on whether we should wait on the CHAP proposal until we also act to reform title V. Could you elaborate for us on any concerns that you might have? Suppose we went ahead with CHAP now looking toward changes in title V in the future. Would that cause any severe problems in your view in terms of trying to change title V?

Dr. HARVEY. CHAP can be implemented most effectively if you have the medical expertise of title V available to the title XIX people because they are just not oriented toward the delivery of health care and case management, that is not their orientation. So if these two programs were to be worked simultaneously, it would be the most effective way and if they were both to be incorporated within a much larger overall structure that governed all child health programs within the Federal Government it would be the most effective way. So you could move ahead with CHAP without title V but it would be nowhere near as effective as if the two were implemented in their changes simultaneously.

Ms. NELSON. Well, I would just point out that the law now speaks quite specifically to require coordination of title V and the medic-aid program.

Dr. HARVEY. Yes.

Ms. NELSON. Would you like to elaborate on why that legislative language has not worked better at the State level? It seems theoretically that the title V agencies should be used right now.

Dr. HARVEY. Well, it should. There are a lot of things that should have happened with EPSDT over the years that have not, and I think that is just one example of them. I think title V needs improvement also. A lot of the orientation in title V over the years has become more one of care delivery rather than of providing demonstration projects, rather than of determining what the total health needs of the children of a State are in making State plans to see that those health needs are met. So we feel that title V needs revision so it returns back to what its primary purpose was rather than a delivery care system and if that happens then we feel it would be much more effective.

Right now there tends to be competition between title V and title XIX attempting to deliver care. That is not the purpose and title V should be providing the expertise as to how that care can best be delivered and how all the needs of the children can be met.

Ms. NELSON. I thank you. I think we will wait for our next witness until we have the Congressman return.

Dr. HARVEY. Thank you.

Mr. MAGUIRE. The next witness is David F. Chavkin representing the National Health Law Program.

Mr. Chavkin.

**STATEMENT OF DAVID F. CHAVKIN, MANAGING ATTORNEY,
NATIONAL HEALTH LAW PROGRAM**

Mr. CHAVKIN. Good afternoon, Mr. Maguire.

The national health law program is the support center funded by the Legal Services Corporation to provide technical assistance to local legal aid programs representing low-income clients in health law matters. In this role, the national health law program has worked with legal services offices in more than 20 States on improving their EPSDT programs.

Occasionally these efforts have involved legislative and administrative advocacy on behalf of EPSDT eligibles. Often, however, these efforts have unfortunately required litigation to enforce the legislative mandates of the EPSDT program. For this reason, our oral testimony today will focus on the adequacy of the enforcement mechanisms contained in the proposed CHAP bills. In our written testimony we will discuss the other important issues involved. [See p. 154.]

I did want to address two of the questions that arose earlier in the hearing. Earlier in the day, Mr. Chairman, you asked the question about the adequacy of the administration provision with regard to scope of dental services, the fact that they only incorporate the medicaid limits. Secretary Davis indicated that that was adequate to assure a minimally adequate program. We believe that is not correct. In fact, the scope that would be applicable under the present medicaid program has allowed State plans which treat only acute pain and infection. That is not the only kind of routine service we want to see available for CHAP eligibles.

The other question raised was on the utilization. We did want to stress the importance of not having any cost sharing in the medicaid CHAP program. The one study that was done on the effect of cost sharing on ambulatory care services during the Reagan administration in California indicated that such cost sharing was penny-wise and pound foolish, that cost sharing was a cost ineffective measure. In fact, a copayment on ambulatory care discouraged the use of that ambulatory care both for necessary care as well as unnecessary care. The result was an increase in the in-patient health care costs, both the incidence of hospitalization and the duration of hospitalization that more than offset the savings. So we strongly support the provisions of your bill as well as Dr. Carter's and the administration's that prohibit any cost sharing on CHAP services.

Realization of the potential of the EPSDT program has been a constant struggle since its enactment. Even today that struggle has been largely unsuccessful in realizing the goals of the program.

Despite the mandate of the 1967 Social Security Amendments that State EPSDT programs be effective by July 1, 1969, HEW did not even propose regulations until December 1970. Final regulations were not adopted until November 1971 and then only after the filing of a lawsuit by the national health law program and the Children's Defense Fund against the Secretary of HEW.

Unfortunately, that case set a tone for the years to come. Taking their lead from the unenthusiastic support of EPSDT by the Secre-

tary, State agencies largely ignored the EPSDT program. In State after State, litigation by program beneficiaries was necessary to force State agencies to obey Federal law. We have included a compendium of many of those cases.

While initially successful in forcing States with no EPSDT programs to establish programs, litigation soon proved to be an extremely limited tool. Once States had established even minimal programs, courts were unwilling to intrude on State discretion that was limited neither by statutory nor regulatory standards of performance. As one Federal judge noted, because of the lack of enforceable goals or standards, all that was required was substantial compliance with the purpose of the program.

If this CHAP legislation is not to go the way of EPSDT, it is absolutely essential that there be meaningful enforceable standards included in the legislation. We are going to discuss those a little later in the testimony. Although principal responsibility for enforcement should be placed on the Secretary, and initial recourse for enforcement should be sought from the Secretary, private rights of action should be authorized to insure that the congressional intent is realized.

Each of the three bills before this committee contains a slightly different enforcement mechanism. Before we examine the adequacy of these specific provisions, some general comments about enforcement tools should be made.

First, any enforcement mechanism should be designed to be used. Although that may seem obvious, the tendency in social welfare programs is to provide for compliance mechanisms that are so severe that they are never used. Thus, the general compliance tool in the medicaid program is to eliminate Federal reimbursement completely for a State program that is out of conformity.

No one takes such a measure seriously because the baby, in this case the CHAP children, would also be thrown out with the bath water. Even the special EPSDT penalty would have such a damaging effect on AFDC beneficiaries that it does not provide a meaningful check on illegal conduct. Penalties must therefore not be so severe that HEW will not impose them or, as happened with the utilization review penalties, that Congress will not permit their imposition.

Second, clear and enforceable standards must be established. These standards are necessary to guide State performance, to evaluate noncompliance, to justify the imposition of penalties or bonuses, and to permit effective monitoring of the program by concerned consumers. The new EPSDT penalty regulations represent a significant first step in this area in quantifying specifically the kind of performance that HEW expects from a State program.

These regulations provide, for example, that States must screen and begin treatment of at least 75 percent of the recipients who request services within 120 days of the initial request or within 120 days of the date of a child's rescreening. Such a standard is enforceable. Compliance, or noncompliance, can be demonstrated by statistical reports. If found out of compliance, a specific plan can be developed to correct deficiencies. If unwilling to comply, a penalty can be imposed which is supported by fact, not conjecture.

Third, there must be an incentive to avoid the penalty. If it is cheaper for States to accept the penalty than provide CHAP services, some States will doubtlessly elect to accept the penalty. When I did a survey for HEW of medicaid programs last fall, EPSDT was discussed with State administrators. Among other things many, many States were very honest that they did an analysis of what the 1 percent penalty would mean to them and even if it were imposed they would end up far ahead in the short run.

None of the proposed enforcement mechanisms fully meets these guidelines. In the past we have therefore urged this committee to explore some very different options. You asked earlier what we could do to make your bill better. One of the possibilities would be to provide for a receivership to actually take over the administration of a State's CHAP program if it was unwilling to comply with Federal law. In the infrequent cases where such a receivership has been utilized, compliance has been rapidly restored and the period of the receivership has been extremely short. Short of this kind of remedy another possibility would be to allow the Secretary one attempt at developing an affirmative compliance plan and if that were unsuccessful to impose a compliance plan on the State by setting specific procedures that the State would have to use to meet the EPSDT standards, at least the minimal standards.

Finally, another option would be to reject any penalty and simply to increase the Federal medical assistance percentage for all medicaid services in those States with effective CHAP programs. Because of the high costs of many medicaid programs, such a bonus of even 1 percent would guarantee compliance while at the same time providing some needed fiscal relief for the States.

Putting those options aside, we believe that the approaches contained in the pending bills are somewhat less effective but we strongly favor the enforcement mechanisms in H.R. 2159 and H.R. 2461 over those in the administration bill.

The administration bill attempts to encourage compliance by a system of fiscal incentives. A State meeting or exceeding CHAP performance standards would be entitled to an increase in its Federal medical assistance percentage for CHAP services. A State that fails to meet compliance standards would be subject to a 5 percent reduction in its matching percentage.

In a time of expanding medicaid costs and limited budgets most States are unwilling to incur additional costs in the short run. This is true despite the projected long term savings from implementation of an effective CHAP program. The administration bill therefore encourages States that are unwilling to comply with Federal performance standards to not establish any program since the maximum penalty would still be only 5 percent.

Moreover, the bonus provision [an increase of up to 20 percent in the matching percentage for CHAP services up to a maximum of 90 percent] is inadequately designed to remedy the major deficiencies in the present EPSDT program. The administration bill places primary emphasis on the percentage of children who are under the care of a continuing care provider and who receive all necessary care and services.

Now since it is based on the children enrolled, and this is the point that you made earlier, Mr. Chairman, these are really not

the children we have to worry about. These children are already in the mainstream of medicine, they are already receiving some care. The major purpose of CHAP must be to identify those children who are not under the care of a provider and who are in need of such care. Such children receive only secondary attention in evaluating performance under the administration bill. The administration bill therefore encourages States to place less emphasis on outreach since the bonus can be maximized by only counting children who are already under the care of a provider.

In contrast, H.R. 2159 and H.R. 2461 specify five specific performance standards which will be evaluated. These are the proportion of eligible families informed, the proportion of such children who are provided assessments, the extent to which services are provided, the proportion of children immunized and the compliance of providers with their obligations under their contracts.

Although not quantified in the statute, these specific factors provide a clear signal to the Secretary of the emphasis areas for monitoring. The Secretary can then establish numerical guidelines for evaluating performance.

Both H.R. 2159 and H.R. 2461 contain financial incentives for State performance. We prefer the formula contained in H.R. 2461 since the availability of 90 percent Federal matching for ambulatory services can help to reorient the child health delivery system away from inpatient services and towards less expensive and more effective ambulatory care. While both bills contain such an incentive, we believe that the assurance of 90 percent matching, even for the wealthier States, will be a stronger incentive for identifying children at an earlier stage.

Both H.R. 2159 and H.R. 2461 also provide for 75 percent matching for outreach services. H.R. 2461, however, authorizes 90 percent matching for outreach services rendered by nonprofit community providers and for followup services rendered by such providers or by health care providers. Outreach is a crucial first step in bringing children into the treatment process. Experiences like those of operation life in Las Vegas have demonstrated the effectiveness of community-based outreach. We therefore support the provision of H.R. 2461 that provides for increased Federal matching for such services. Such services will be more effective and, in the long run, will lessen costs.

I understand you are going to be hearing from some of the welfare mothers in Baltimore who have demonstrated the effectiveness of this kind of community based outreach. Whether or not it is unfair in some people's minds, the point is that the financial incentive is going to encourage the kind of service that you want to see provided. If community based outreach is more effective, then that is where you have to put the bucks because that is where they will be maximized in terms of delivery of services.

Finally, both bills provide for a 20 percent penalty on administrative costs for those States that are out of compliance with CHAP standards. We support the notion of penalizing administrative costs rather than services. However, in practice, most States deal with a single pot of money that is available to fund the medicaid program. The reduction of Federal matching for administrative costs will necessarily require an increase in State appropriations for adminis-

tration or will result in a general reduction in medicaid services to make up the deficit. We fear that most States will choose the latter course.

We therefore urge that principal reliance for enforcement be placed on the bonus provisions of the bills. If a penalty provision is necessary, it should at least provide for a sliding scale reduction in Federal matching rather than 20 percent in the administrative costs. Otherwise, a State that is slightly out of compliance would be treated the same as a State that never even implemented a program. That type of penalty therefore encourages conduct that we want to avoid.

Thank you for the opportunity to appear before the committee this afternoon. If there are any questions, I would be happy to answer them.

[Testimony resumes on p. 172.]

[Mr. Chavkin's prepared statement and attachment follow:]

STATEMENT OF DAVID F. CHAVKIN, MANAGING ATTORNEY,
NATIONAL HEALTH LAW PROGRAM

The National Health Law Program is the support center funded by the Legal Services Corporation to provide technical assistance to local legal aid programs representing low-income clients in health law matters. In this role, the National Health Law Program has worked with legal services offices in more than 20 states on improving their EPSDT programs.

Occasionally, these efforts have involved legislative and administrative advocacy on behalf of EPSDT eligibles. Often, however, these efforts have unfortunately required litigation to enforce the legislative mandates of the EPSDT program. For this reason, our oral testimony focussed on the inadequacy of the enforcement mechanisms contained in the proposed CHAP bills. This written testimony discusses enforcement as well as the other important issues involved.

Realization of the potential of the EPSDT program has been a constant struggle since its enactment. Even today, that struggle has been largely unsuccessful in realizing the goals of the program.

Despite the mandate of the 1967 Social Security Amendments that state EPSDT programs be effective by July 1, 1969, HEW did not even propose regulations until December, 1970. Final regulations were not adopted until November, 1971, and then only after the filing of a lawsuit by the National Health Law Program and the Children's Defense Fund against the Secretary of HEW. National Welfare Rights Organization v. Richardson, No. 2091-71 (D.D.C. 1971).

That case set a tone for the years to come. Taking their lead from the unenthusiastic support of EPSDT by the Secretary, state agencies largely ignored the EPSDT program. In state after

state, litigation by program beneficiaries was necessary to force state agencies to obey federal law. Many of those cases are listed in Appendix 1.

While initially successful in forcing states with no EPSDT programs to establish programs, litigation soon proved to be an extremely limited tool. Once states had established even minimal programs, courts were unwilling to intrude on state discretion that was limited neither by statutory nor regulatory standards. As one federal judge noted, because of the lack of enforceable goals or standards, all that was required was substantial compliance with the purpose of the program.

If this CHAP legislation is not to go the way of EPSDT, it is therefore essential that clear, enforceable standards be established and that incentives be incorporated to encourage compliance with these standards. It is often impossible to correct noncompliance when a statutory or regulatory scheme has been devised which discourages compliance through its reimbursement system. Federal reimbursement should therefore be utilized to encourage compliance by insuring that it is always more profitable for the state to comply.

When enforcement becomes necessary, it should meet several general requirements. First, any enforcement mechanism should be designed to be used. Although that may seem obvious, the tendency in social welfare programs is to provide for compliance mechanisms that are so severe that they will never be used. Thus, the general compliance tool in the Medicaid program is to eliminate federal reimbursement completely for a state program that is out of conformity.

No one takes such a measure seriously, because the baby (in this case the CHAP children) would also be thrown out with the bath water. Even the special EPSDT penalty would have such a damaging effect on AFDC beneficiaries that it does not provide a meaningful check on illegal conduct. Penalties must therefore not be so severe that HEW will not impose them, or that Congress will not sanction their imposition. This has been the situation, most recently, with the utilization review penalties under Medicaid.

Second, clear and enforceable standards must be established. These standards are necessary to guide state performance, to evaluate noncompliance, to justify the imposition of penalties or bonuses, and to permit effective monitoring of the program by concerned consumers. The new EPSDT penalty regulations represent a significant step in this area.

These regulations provide, for example, that states must screen and begin treatment of at least 75% of the recipients who request services within 120 days of the initial request or within 120 days of the date of a child's rescreening. Such a standard is enforceable. Compliance, or noncompliance, can be demonstrated by statistical reports. If found out of compliance, a specific plan can be developed to correct deficiencies. If unwilling to comply, a penalty can be imposed which is supported by fact, not conjecture.

Third, there must be an incentive to avoid the penalty. If it is cheaper for states to accept the penalty rather than provide CHAP services, some states will doubtlessly elect to accept the penalty. In fact, some states made just such an analysis after the enactment of the EPSDT penalty provision and concluded that it was to their advantage to suffer the 1% penalty on AFDC

funds rather than spend what was necessary to establish a viable EPSDT program.

None of the proposed enforcement mechanisms fully meets these guidelines. In the past, we have recommended some very different options. One of these was an authorization for the Secretary to actually take over the administration of a state's CHAP program if it was unwilling to comply with federal law. In the infrequent cases where such a receivership has been utilized, compliance has been rapidly restored and the period of the receivership has been extremely short.

Another approach would be to authorize the Secretary to develop a compliance plan which a state found out of compliance would have to implement. Thus, once voluntary efforts at compliance had proven unsuccessful, the Secretary could impose specific remedial steps which would bring the state plan into compliance with federal standards. While the State would be able to maintain control over its program, noncompliance for indefinite periods would not be tolerated.

A third option would be to reject any penalty and simply to increase the federal medical assistance percentage for all Medicaid services in those states with effective CHAP programs. Because of the high costs of many Medicaid programs, such a bonus of even 1% would guarantee compliance while, at the same time, providing some needed fiscal relief for the states.

We believe that these approaches would be effective in realizing the potential of the CHAP program. While the remedies contained in the pending bills may be less effective, we strongly favor the enforcement mechanisms in H.R. 2159 and H.R. 2461 over those in H.R. 4053.

The Administration bill attempts to encourage compliance by a system of fiscal incentives. A state meeting or exceeding CHAP performance standards would be entitled to an increase in its federal medical assistance percentage for CHAP services. A state that fails to meet compliance standards would be subject to a 5% reduction in its matching percentage.

In a time of expanding Medicaid costs and limited budgets, most states are unwilling to incur additional costs in the short run. This is true despite the projected long term savings from implementation of an effective CHAP program. The Administration bill therefore encourages states that are unwilling to comply with federal performance standards to not establish any program since the maximum penalty would still be only 5%.

Moreover, the bonus provision (an increase of up to 20% in the matching percentage for CHAP services up to a maximum of 90%) is inadequate to remedy the major deficiencies in the present EPSDT program. The Administration bill places primary emphasis on the percentage of children who are enrolled in the program, who are under the care of a continuing care provider, and who receive all necessary care and services.

These are not the children we have to worry about because these children are already aware of the CHAP program and are already likely to get some medical care. The major purpose of CHAP must be to identify those children who are not under the care of a provider and who are in need of such care. Such children receive only secondary attention in evaluating performance under the Administration bill. The Administration bill therefore encourages states to place less emphasis on outreach since the bonus can be maximized by only enrolling children who are already

under the care of a provider.

In contrast, H.R. 2159 and H.R. 2461 specify five specific performance standards which must be evaluated. These are the proportion of eligible families informed, the proportion of such children who are provided assessments, the extent to which services are provided, the proportion of children immunized, and the compliance of providers with their obligations under their contracts.

Although not quantified in the statute, these specific factors provide a clear signal to the Secretary of the emphasis areas for monitoring. The Secretary can then establish numerical guidelines for evaluating performance.

Both H.R. 2159 and H.R. 2461 contain financial incentives for state performance. We prefer the formula contained in H.R. 2461 since the availability of 90% federal matching for ambulatory services can help to reorient the child health delivery system away from inpatient services and towards less expensive and more effective ambulatory care. While both bills contain such an incentive, we believe that the assurance of 90% matching, even for the wealthier states, will be a stronger incentive for identifying children at an earlier stage.

Both H.R. 2159 and H.R. 2461 also provide for 75% matching for outreach services. H.R. 2461, however, authorizes 90% matching for outreach services rendered by nonprofit community providers and for follow-up services rendered by such providers or by health care providers. This financial incentive will encourage states to contract with such groups. Since these groups have demonstrated greater effectiveness in performing outreach, a subsequent penalty will more likely be unnecessary to remedy poor performance.

Finally, both of these bills provide for a 20% penalty

on administrative costs for those states that are out of compliance with CHAP standards. We support the notion of penalizing administrative costs rather than services. However, in practice, most states deal with a single pot of money that is available to fund the Medicaid program. The reduction of federal matching for administrative costs will necessarily require an increase in state appropriations for administration or will result in a general reduction in the Medicaid services to make up the deficit. We fear that most states will choose the latter course.

We therefore urge that principal reliance for enforcement be placed on fiscal incentives in the bills to encourage performance. If a penalty provision is adopted, it should at least provide for a sliding scale reduction in federal matching. Otherwise, a state that is slightly out of compliance would be treated the same as a state that never even implemented a program.

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ISSUE:

Residency

PROBLEM:

H.R. 4053 does not amend current law to require that an individual live, not reside, in the State where Medicaid is requested.

RECOMMENDATION:

Add section 108 to H.R. 4053 to read as follows:

Section 108(a): Section 1902(a)(16) is amended by striking out "who are residents of the State" and inserting in lieu thereof "who are determined to be living in the State."

(b)Section 1902(b)(2), as redesignated by section 101(b)(1) of this Act, is amended by striking out "resides in the State" and inserting in lieu thereof "lives in the State (in accordance with standards established by the Secretary)".

DISCUSSION:

Current Medicaid residency requirements state that, in order to be eligible for Medicaid, State residency is required. A State resident is defined as one "who is living in the State voluntarily with the intention of making his home there and not for a temporary purpose." This makes it very difficult for institutionalized and migrant children to establish residency. Thus, many of these children are unable to qualify for Medicaid.

Both H.R. 2159 and H.R. 2461 address this issue. We strongly urge that H.R. 4053 adopt such an approach.

ISSUE:

Dental services

PROBLEM:

H.R. 4053 would allow states to impose severe limits on the dental services available under CHAP.

RECOMMENDATION:

Amend section 103 of H.R. 4053, by adding, in clause (III) on p. 10 at line 3, after the words "section 1905(a)" the following:

"which may not be less in amount, duration and scope than minimum limits which the Secretary may prescribe and which shall include".

DISCUSSION:

H.R. 4053 would allow states to impose limits on the amount, duration and scope of CHAP services subject only to the general limits on amount, duration and scope found in the Medicaid program. These limits have proven inadequate in insuring that medically necessary care is not excluded from the state plan. Additional safeguards are therefore necessary.

Severe dento-facial deformities can become both physically and psychologically damaging. It is therefore necessary that provision for such services be included under CHAP. Both H.R. 2159 and H.R. 2461 provide for coverage of orthodontia in extreme cases. We strongly urge that the final legislation provide for these services.

ISSUE:

Required Services

PROBLEM:

H.R. 2159 and H.R. 2461 expand the scope of services only for those children who have received a timely periodic child health assessment.

RECOMMENDATION:

Amend section 4(a)(1)(iii) [in H.R. 2159 at p. 8, l. 20; in H.R. 2461 at p. 8, l. 9], by striking "who has received a timely periodic child health assessment (as defined in Section 1905(n)), " and inserting in lieu thereof "who is eligible for Medicaid,".

DISCUSSION:

The provisions in both H.R. 2159 and H.R. 2461 expand current services only for those children who have been assessed. As a result, CHAP children who are determined, outside of an assessment, to need treatment which is only available to assessed children must then go through an assessment. This delay in treatment of a medical condition can only lead to unnecessary discomfort to the child and/or advancement of the condition which may create a need for more expensive treatment.

In contrast, H.R. 4053 provides for a more limited scope of services but allows any Medicaid eligible child to receive these services regardless of whether the child has been assessed. While we support the concept of assessments for all children, we do not believe that the scope of services should be dependent on an assessment. We therefore urge that the recommendation be adopted.

ISSUE:

Performance Standards

PROBLEM:

Section 106(d) of H.R. 4053 considers only those children enrolled in the State program who are either receiving continuing medical care or who are receiving timely assessments and treatment in evaluating program effectiveness.

RECOMMENDATION:

Amend Section 106(d) in H.R. 4053 by striking out "enrolled in" and inserting in lieu thereof "eligible for".

DISCUSSION:

H.R. 4053 measures program effectiveness by considering only those children enrolled in the State's program who are under continuing care or who are receiving timely assessments and treatment. Greater weight is given to those children under continuing care agreements.

Under this approach, states can maximize reimbursement by limiting enrolled children to those covered by continuing care agreements. It is necessary, however, that this measurement include all program eligible children and not just those who are enrolled and already receiving health care. As it is written, the legislation does not give the state any incentive to bring new (eligible) children into the health care system.

ISSUE:

Notice to all Medicaid recipients

PROBLEM:

Under current law, states do not notify all Medicaid recipients of the availability of EPSDT services.

RECOMMENDATION:

Adopt a provision to read as follows:

"The state plan shall...(xx)provide that the State agency shall inform all families in the State receiving Medicaid benefits of the availability of child health assurance services under the plan of such State approved under Title XIX,".

DISCUSSION:

Section 107(c) of H.R. 4053 contains a similar notice requirement. However, notice would be limited to AFDC children. Limiting notice to AFDC recipients leaves out a significant number of children eligible for Medicaid (for example, SSI children). It is important that all Medicaid eligible children, and not just AFDC children be alerted to the availability of these services.

ISSUE:

State maintenance of effort

PROBLEM:

None of the proposed bills contains an adequate maintenance of effort provision to assure that states will maintain current income and resources standards and current scope of services.

RECOMMENDATION:

Adopt a provision to read as follows [amending sections 8(2) of H.R. 2159 and H.R. 2461]:

"No State shall (1) reduce the standards of income or resources for eligibility for medical assistance for individuals under the age of twenty-one below the applicable standards in existence on the date of the enactment of such Act, or (2) reduce the amount, duration, or scope of medical assistance (other than inpatient care and services) made available to individuals under the age of twenty-one below the applicable medical assistance available on such date of enactment."

DISCUSSION:

States should not be allowed to reduce the standards of their current child health program. H.R. 2159 and H.R. 2461 both have provisions which would reduce the reimbursement to states which attempted to cutback on their child health programs. This penalty may be insufficient to guarantee compliance. Mandatory language should therefore be included as described, since it could easily be enforced in the courts by either HEW or a private party. Moreover, resource standards, which are a crucial eligibility factor, should be covered by the provision.

ISSUE:

Outreach by community-based organizations

PROBLEM:

H.R. 2159 and H.R. 4053 do not contain any incentives to encourage states to utilize the services of community-based organizations for outreach.

RECOMMENDATION:

Adopt the approach found in section 7 of H.R. 2461 which authorizes a 90% federal matching rate to community-based and non-profit organizations providing outreach.

DISCUSSION:

Outreach is a key element if the potential of CHAP is to be realized. Community-based organizations, like Operation Life in Las Vegas, have demonstrated the effectiveness of this approach. The 90% federal matching rate would provide a strong incentive for states to contract with more of these organizations to provide outreach services. This would insure that more children would be reached and brought into the CHAP delivery system.

ISSUE:

Continuing Medicaid eligibility to children placed in juvenile institutions and eligibility for hard-to-place adopted children.

PROBLEM:

H.R. 4053 does not provide Medicaid eligibility for hard-to-place adopted children or continuing eligibility for children who have been placed in juvenile institutions.

RECOMMENDATION:

Adopt the approach found in sections 3(d) and 14 in H.R. 2159 and H.R. 2461.

DISCUSSION:

The Administration bill does not extend coverage to hard-to-place adopted children or to children in juvenile institutions. The provisions in H.R. 2159 and H.R. 2461 would extend Medicaid eligibility to children adopted from foster care facilities, who have been hard to place because of a medical condition requiring medical care, regardless of the income level of the adopting family, and to children placed in juvenile institutions, if they or their families had been eligible for Medicaid before being admitted to that institution. Both of these provisions would provide medical care to many children who would otherwise have little or no access to such services. To the extent that such services are already being provided by the states, federal financial participation will now be available. In addition, federal standards will now be applicable for evaluating compliance. We therefore urge that these provisions be added to H.R. 4053.

ISSUE:

Child Health Program Coordination

PROBLEM:

H.R. 4053 does not require coordination of health care services provided under Title V (Maternal and Child Health) and Title XIX (Medicaid) of the Social Security Act.

RECOMMENDATION:

Adopt the approaches found in section 11 of H.R. 2159 and H.R. 2461.

DISCUSSION:

Due to a lack of coordination of the parts of Title V and Title XIX child health programs, there is inefficient use of services available to children qualifying for these programs. With a combined effort on the parts of Title V, Title XIX, and other federally-funded programs providing health services, a much more effective and efficient child health care delivery system could be achieved. Although the Administration has begun such coordination through its "CHAMP" initiative, a specific legislative mandate should be enacted. The performance of HEW can then be evaluated against this standard.

ISSUE:

Provider Agreements

PROBLEM:

Many states do not utilize written provider agreements in their EPSDT programs which clearly specify the responsibilities of providers under the program.

RECOMMENDATION:

Adopt the language contained in section 4(e) of H.R. 2159 and H.R. 2461 and in section 102(b) of H.R. 4053 which requires written provider agreements specifying the responsibilities of providers.

DISCUSSION:

In a number of states, provider noncompliance with screening packages has been a serious problem. In Massachusetts, for example, providers have often been unwilling to perform vision, hearing and lead screening despite the State specification of these services in the screening package. As a result, these services often are not received by children.

All providers must sign provider agreements under the present Medicaid law. This requirement should be expanded for the CHAP program to clearly specify the responsibilities of the providers to render services. This contract would also serve as the standard for state monitoring of provider compliance.

EPSDT LITIGATION

(Selected Cases)

1. California:

Telles v. California Health and Welfare Agency
No. C73-0967 WHO (N.D. Cal.)

2. Colorado:

Lovato v. Shea
No. C-4790 (D. Colo.)

3. Connecticut:

Connecticut State Employees' Union v. White
No. 14923 (D. Conn.)

4. Indiana:

Stanton v. Bond
No. 73-H-184 (N.D. Ind.)

5. Illinois:

Illinois Welfare Rights Organization v. Edelman
No. 73Cl398 (N.D. Ill.)

6. Kentucky:

Louisville Welfare Counseling Storefront v. Dawson
No. C-75-0163L(B) (W.D. Ky.)

7. Maine:

Brooks v. Smith
No. 1308 (Sup. Jud. Ct.)

8. Massachusetts:

Vega v. Scoville
No. 74-5877 (D. Mass.)

9. Michigan:

Dominguez v. Milliken
No. G-198-72 (W.D. Mich.)

10. Minnesota:

Minnesota Recipients' Alliance v. Likins
No. 4-75-422 (D. Minn.)

11. Ohio:

Morland v. Gilligan
No. C74-53 (N.D. Ohio)

12. New York:

Woodruff v. Lavine
No. 73-5333 (S.D.N.Y.)

13. Pennsylvania:

Philadelphia Welfare Rights Organization v. Shapp
No. 73-290 (E.D. Pa.)

14. Vermont:

Harris v. Candon
No. 74-49 (D. Vt.)

15. Wisconsin:

Wisconsin Welfare Rights Organization v. Newgent
No. 75-Cl02 (E.D. Wis.)

Mr. MAGUIRE. Thank you.

You noted that there was a potential problem with the administration's proposed performance indicated just as I had earlier; that is, outreach would be undercut to the extent that we use a formula that provides a bonus in relation to children who are already under care, but presumably you also are looking at the problem that results from counting only against enrolled children. It is essentially the same point.

Mr. CHAVKIN. That is right, the language in the administration bill in section 106 provides that you consider the proportion of children under the age of 18 enrolled in a State's program. If you change that to the number of children who are eligible in the program, then you set up a different incentive. You then have the incentive for encouraging the continuing treatment while also encouraging outreach to try and bring children who are not under the care of any providers into the program.

Mr. MAGUIRE. The administration maintains, though, that increasing the match for outreach to 75 percent balances out whatever disadvantages without being contained in their method of computing. Do you agree with that or disagree?

Mr. CHAVKIN. It increases the likelihood of outreach. It does not guarantee it because the major costs are going to be for services and by tying the floating percentage bonus for services to the percentage of enrolled children who are under a continuing care agreement, you have a bias in the other direction that I think is going to more than balance off the additional Federal moneys. I don't think 75 percent is going to do it.

Mr. MAGUIRE. You say it does not equalize it, it falls short.

Mr. CHAVKIN. That is right.

Mr. MAGUIRE. And on balance the administration approach would be an additional disincentive for additional outreach, is that right?

Mr. CHAVKIN. That is right.

Mr. MAGUIRE. Dr. Harvey talked about the written agreement with providers and he felt that a written agreement would not be helpful in encouraging providers to participate. I wonder if you would comment on the written agreement matter as to its desirability in tacking down specific obligations of the provider on the one hand versus whatever reticence providers might feel about entering into such an agreement on the other.

Mr. CHAVKIN. First of all, all medicare providers have to sign a general provider enrollment agreement to get into the program and get a medicare number. That requirement already exists. I know there are some States that don't do that.

Mr. MAGUIRE. His argument was that whatever is already there is adequate and that whatever the law was you would be obligated to follow the provisions of the law whether that pertained to any new law on children's health assessment programs or anything else.

Mr. CHAVKIN. Well, the entry of that provider agreement did discourage many providers from participating. It came in as part of the part of the antifraud and abuse amendments. Many providers saw that as a means of trying to catch them and they became very, very concerned about the effect that that would have on their

potential criminal liability. Since there already is such a requirement, we think the provider agreement is really essential. The notion of a provider signing a billing form even if it is a uniform billing form that says at the bottom that everything in here is done consistent with the State regulation does not mean very much in California where Dr. Harvey is from. The administrative code is very, very lengthy and I don't feel confident that all the doctors are clear on that. A specific provider agreement, whether it is for continuing care or for isolated providers, would set very, very clear expectations of the program and the obligations that they would have and I think it is a desirable feature in insuring that the care is going to be comprehensive.

Mr. MAGUIRE. But this would be an additional paper.

Mr. CHAVKIN. It could be the same piece of paper.

Mr. MAGUIRE. It could be the same piece of paper.

Mr. CHAVKIN. In Massachusetts we have a very, very serious problem with pediatricians who have been unwilling to provide as a part of the screening package, vision care screening and hearing screening and lead screening. They just refuse to do it. They don't believe it is something that they want to do. This agreement would attempt to rectify many of those deficiencies.

Mr. MAGUIRE. Well, is it your judgment that pediatricians who have already been willing to sign a written agreement would not be likely to be deterred by being asked to sign an additional written agreement, and that those who would be deterred by signing a written agreement with respect to providing services under CHAP would already have been placed outside the program as a result of their earlier reticence to sign for the other agreement? Is that your position?

Mr. CHAVKIN. I think there are probably some additional providers who will drop out of the program. There should be a question in all of our minds whether we want those providers in the program if they are not willing to do the complete assessments that are required under the law, but I think that it would be naive to think that some providers would not drop out on that basis just as they drop out because of the fee levels, some because the States are not meeting the requirements for processing times of checks under H.R. 3, and for other reasons as well.

Mr. MAGUIRE. Now you mentioned quite correctly that the financial incentives in my bill are to increase the match for assessed children for ambulatory services to 90 percent and you seem to think that that is an adequate incentive, but my proposal also includes an increase of 10 percentage points to the match for inpatient care as well. What is your judgment on that?

I mean obviously that is designed to help increase incentives for the total CHAP program. I suppose to the extent that you increase the incentive or increase the matching percentage for inpatient you detract from whatever additional incentive for ambulatory that you were trying to achieve. What do you think about this additional 10 points and how that balances with the 90 percent for ambulatory?

Mr. CHAVKIN. I think the most crucial incentive in your bill is the 90-percent incentive for ambulatory care services. My sense is that most children who are in need of inpatient services are going

to get those services, that the incentive that you have there is less of a factor in altering State and provider behavior and in insuring delivery of care.

Mr. MAGUIRE. Now with respect to the new EPSDT penalty regulations which you refer to on page 3, I wonder how enforceable you think these regulations will be and whether you want to add anything for the record here as to other provisions in the regulations which you think are desirable or need to be improved.

Mr. CHAVKIN. A fairly extensive set of recommendations were developed as part of the House report last year and it would probably be best, because they are fairly extensive to try and respond to that in writing. Wendy Lazarus and I worked with Karen on developing those kinds of standards and they were included in the House report language, so I think that is probably the best answer I can give on that. We can address that in our written testimony in somewhat greater length.

Mr. MAGUIRE. Fine. Did you want to comment on the enforceability question? Can you think up any incentives that one might include here in order to enforce the regulations as opposed to incentives to get people to provide services?

Mr. CHAVKIN. We had originally come up with a very, very different incentive program or bonus program. That was that any State that did not meet the standards would have its gasoline allocations cut off. We decided that was the one foolproof method of effecting compliance with this program.

Mr. MAGUIRE. It is very funny that you should say that because I have been saying to colleagues and friends that it is amazing how quickly the attention of the public and of the media focuses on any issue which bears any relationship to the amount of gasoline that one can pump into one's tank and its price. I found myself constantly being interviewed by everyone in sight with respect to that question. When we are dealing with questions like this that relate to the future health of all the children in our society, somehow people's attention is not focused or their efforts as galvanized as when you are dealing with the price of a gallon of gasoline. That is essentially the point you are making, isn't it?

Mr. CHAVKIN. That is the point.

Mr. MAGUIRE. Mr. Leland, what are we going to do? I was just going to draw you into this philosophical discussion.

Mr. LELAND. I thought maybe you needed some gasoline.

Mr. MAGUIRE. At any rate I think it does reflect poorly on both our priorities and on our ability to focus on longer term as opposed to shorter term issues.

Mr. CHAVKIN. Representative Leland asked a question earlier today about why the effect on Texas is as great under the new regulations. As you are probably aware in the medicaid program, Texas has a lower matching rate. It also has one of the most limited medicaid programs for children of any of the States.

Mr. LELAND. Absolutely.

Mr. CHAVKIN. So that you are going to have a significant increase in the number of eligibles and you are not going to receive as great an additional Federal bonus for treating those as some of the other States, and that is why the percentage costs and the total costs for Texas will be somewhat larger.

Mr. LELAND. You don't think that is fair though.

Mr. CHAVKIN. Fair that the children of Texas should now have medical care and treatment?

Mr. LELAND. No, fair that they don't get as much from the Federal Government as other States.

Mr. CHAVKIN. Well, they would under Representative Maguire's bill.

Mr. LELAND. I understand that. OK, I hear you. What I am trying to get at—

Mr. MAGUIRE. That is the Maguire-Waxman-Leland bill.

Mr. LELAND. Thank you. I will take any place on that.

Let me get a little more philosophical right now.

You might not want to print this.

Mr. MAGUIRE. If the gentleman will defer to the chairman, the gentleman is going to have to make his own decision whether the gentleman wants something printed by the reporter.

Mr. LELAND. It does not matter.

Mr. MAGUIRE. All right.

Mr. LELAND. I just got back from Cuba and now you know what I am talking about.

Mr. MAGUIRE. Perhaps you better not print it.

Mr. LELAND. I was overwhelmed, I realized the philosophical or the ideological differences between this country and Cuba and I also realized that we still suffer in this country from the legacy of McCarthyism, et cetera. Domestic priority is first and foremost to kids in Cuba in it's very depressed economic situation. One of the things that they do is they guarantee the kids I think from the time that they are born until they are 12 years old at least 1 liter of milk a day and education and adequate health care to support their needs. Yet this country has still not addressed itself to that in terms of priorities.

I realize that a lot of people think we are doing all that we can for children. But I have some very serious problems in having come back from Cuba. I realize that there is a party line over there that they espouse but at the same time I realize and feel that their kids are really taken care of because they recognize that the children are the future of their country.

Yet in my district 27.7 children die out of each 1,000 before age 1. In Houston, where we talk about Texas being wealthy, we talk about Houston being the mecca—if you will pardon the reference—the mecca of this country in terms of its growth and its development. All of the oil corporate headquarters are in my district and in the shadows of their great buildings there is extreme poverty. Black kids and Hispanic kids in particular are dying, and we have not addressed ourselves to how to deal with that kind of situation.

There is some kind of contradiction there and that is why I am glad I am in the company of Andy Maguire and Henry Waxman. You don't have to comment on Cuba or anything else, but how did we get there? How do we deal with taking care of the children of our society? Every one of our children ought to be guaranteed a safe life and at least the ability to pursue happiness in our country. Yet they are not.

Mr. CHAVKIN. You don't have to refer to Cuba. The administration as part of its initial national health insurance presentation

went through a list of the infant mortality rates. When you see how low on the list the United States is as a whole compared to other countries and when you look at some of the pockets—not just Houston but Watts and Los Angeles and I am sure there are portions of Newark—

Mr. LELAND. D.C.

Mr. CHAVKIN [continuing]. D.C. that are as bad. It certainly does demonstrate not just a lack of commitment to child health, but a lack of commitment to adequate health, adequate welfare, adequate housing for all citizens. To think that you can deal just with child health independent of welfare reform or any of the other measures is a mistake, but this is one focus and it is one step toward dealing with a lot of those kinds of concerns. The fact that we have tolerated the level of non—of blatant noncompliance with EPSDT, and on a more philosophical level a lack of realization of the program for so many years, is very disconcerting. It is disconcerting to me as an advocate and it should be disconcerting to the legislators.

Mr. LELAND. I hear you. The thing is that, for instance, you know they take it somewhat to an extreme in a way—in Cuba, I am talking about. Ninety-seven percent of the babies born in Cuba are born in hospitals and the only reason there is a 3 percent not born in hospitals is because the women don't make it to the hospitals, or there are some older women who don't necessarily want to go to hospitals for some reason. But, you know, that attention, that priority, is incredible. It seems to me that in a country like this with the resources that we have guess this is my opening statement, and my closing statement, Mr. Chairman—it seems to me that this country ought to deal with children as their highest priority, and we are not doing it.

Mr. CHAVKIN. In Cuba they are delivering in hospitals and in Holly Springs, Miss. they deliver them in hospital parking lots.

Mr. LELAND. I hear you.

Mr. CHAVKIN. That has been in the process of a title VI investigation for some time. In Texas chicano families are sent back across the border to deliver the babies in Mexico even when they are American citizens. It is very troublesome.

Mr. LELAND. Thank you, Mr. Chairman.

Mr. MAGUIRE. Thank you.

Just a couple of final questions, Mr. Chavkin. You suggested that if a State isn't meeting the requirements under the program that HEW should be able to take over the administration of the State program. Do you think they have the administrative capacity to do that?

Mr. CHAVKIN. I think that they would develop it very quickly. I have had experience with this on a personal level. We had a county in California that decided to secede from the State for political reasons. We were able to impose a receivership on the basis of moral bankruptcy. It was the first time it had been done.

Mr. MAGUIRE. Did you succeed?

Mr. CHAVKIN. We succeeded and the county was taken over by the State for a quarter, 3 months. The State developed the administrative capability to do it.

Mr. MAGUIRE. The administration has not had the administrative capability to run a decent EPSDT program even when they were not in charge of operating the program in individual States, so I am not sure the answer is quite as easily provided as what you might suggest.

Mr. CHAVKIN. Well, I think that there is a difference between this administration and some of the previous ones. I think we have seen that in some things like the EPSDT regs which make the best, I think, of a bad situation. I think the 1-percent penalty is good. I think they have done about what they can in terms of trying to set up some standards to try to enforce that. There is the expertise to take a step short of receivership and there are some very, very fine people involved in child health in the Department who could set up the corrective procedures or who could involve the outside people necessary to make an EPSDT program or CHAP program that would meet not only minimal standards but the kinds of performance standards we want to see in every State.

Mr. MAGUIRE. I suppose a larger issue would also be whether this program and medicaid generally ought to be essentially a State run program. Do you think that is the best way for us to do these things?

Mr. CHAVKIN. I very strongly believe in a federalized medicaid program, having litigated on that and having seen the gaps in eligibility that exist today, the limits of 10 hospital days where you have got a burn victim who needs 40 and does not get coverage even though it is necessary medical care. When you see the kinds of political decisions being made at a State level obviously from that experience over the last years, I am a very strong advocate for federalized administration and federalized minimum levels of eligibility and amount, scope and duration.

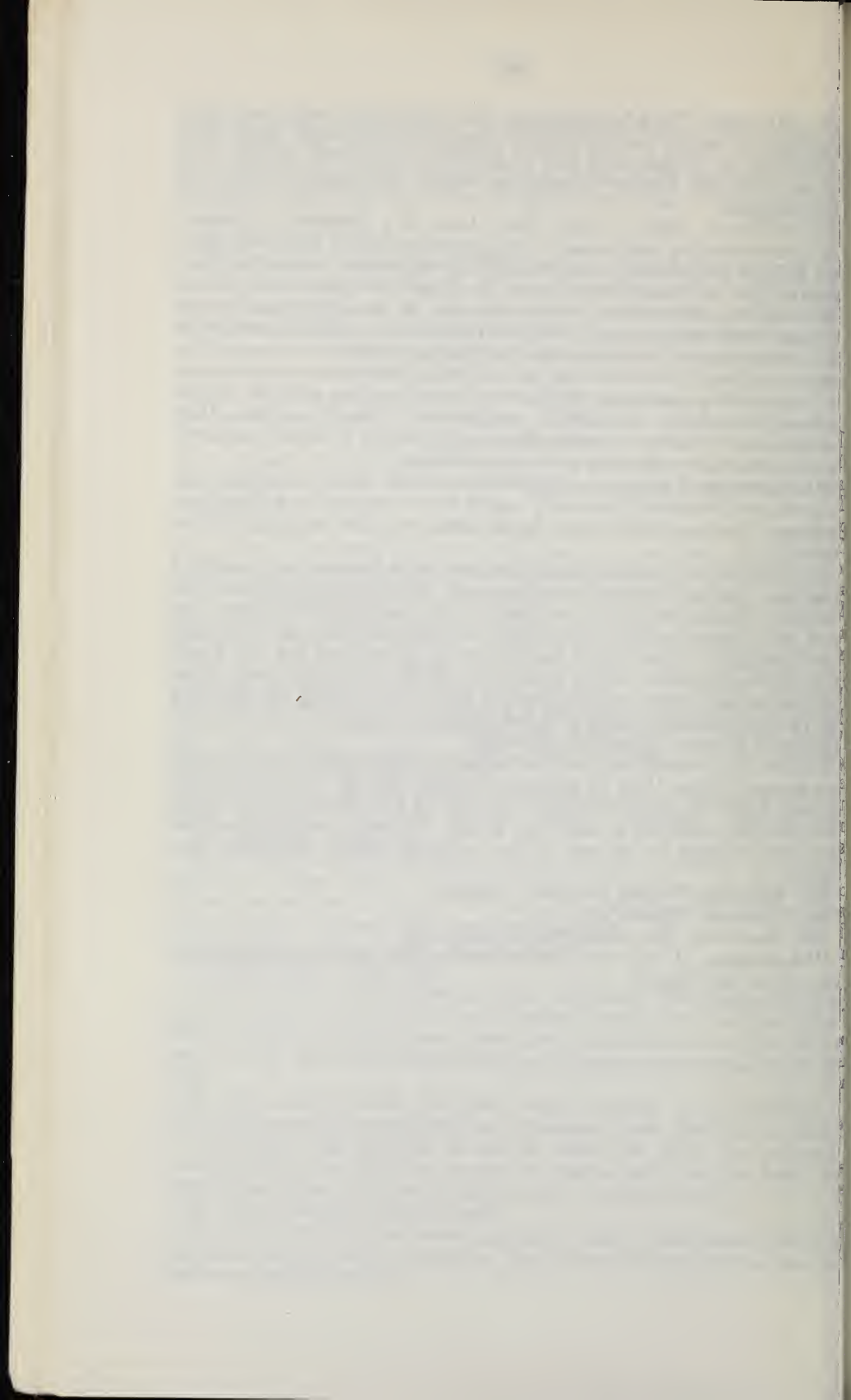
I think that would be a partial answer because then you focus on one person rather than 53 jurisdictions and of course it would help us deal with the problem that it is not 54 jurisdictions no matter what we do. Arizona is still not going to have a program unless they are dragged in as part of the national health insurance program.

Mr. MAGUIRE. Thank you, Mr. Chavkin.

Mr. CHAVKIN. Thank you.

Mr. MAGUIRE. The committee is adjourned.

[Whereupon, at 3:45 p.m., the subcommittee adjourned subject to the call of the Chair.]



CHILD HEALTH ASSURANCE ACT OF 1979

MONDAY, JUNE 11, 1979

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT,
COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE,
Washington, D.C.

The subcommittee met, pursuant to notice, at 10 a.m., in room 2318, Rayburn House Office Building, Hon. Henry A. Waxman, chairman, presiding.

Mr. WAXMAN. Today we are continuing our hearings on legislation to establish a child health assurance program.

The testimony presented before the subcommittee last Thursday provided the members with much useful advice on the relative merits of the various proposals before us.

I hope we can continue that process today, as we consider specific benefit provisions in the bills, particularly those relating to dental care and mental health services, and examine the importance of outreach to a successful implementation of a child health program.

Mr. Maguire?

Mr. MAGUIRE. Thank you, Mr. Chairman.

We continue today what is turning out to be a rather extensive inquiry into how best to serve truly compelling health needs of our Nation's children. I am pleased, as I know you are, that we have an impressive array of witnesses that will enable us to get a better understanding of some of the more specific but crucially important issues of child health assurance proposals.

The dental health of children is one of the most important but unfortunately most neglected areas in the current medicaid system. It's a national embarrassment that in this area of truly effective preventive health care almost 70 percent of the poor children under the age of 15 have never seen a dentist.

We have an excellent panel to assist us in this area.

The President's Commission on Mental Health took special note of the mental health care of children and adolescents and found them to be an especially underserved group. It's very alarming that suicide is the third leading cause of death for adolescents and that the rate has tripled in the last two decades.

We have a number of important organizations involved in mental health that will give us suggestions in this area.

No matter how fine a child program is developed it will be useless unless we get children and families to participate. Thus, the issue of outreach is critical.

There has been clear evidence that local groups have been most effective in outreach, and we have an excellent panel to discuss what are the most effective strategies for outreach.

In order to assure that children's health is promoted we must have adequate data systems to ascertain how effective the programs are. There must be adequate information to properly administer CHAP and maintain accountability.

We have a panel to address those issues. Congressman Leland of Texas has introduced a very important bill, which I heartily support, that is complementary to the CHAP proposal to develop more effective programs to assure that children are receiving adequate nutrition.

If CHAP is to be successful in preventing medical problems, thus assuring health, it is essential that such basic nutritional needs are assessed and provided for. We have an excellent panel on those issues as well.

Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Mr. Maguire.

Our first witness is Dr. James Kerrigan, American Dental Association. As Mr. Maguire mentioned, we have a number of other witnesses testifying on various aspects of the proposals.

We have your submitted testimony, which will be made part of the record.

We would like to ask all witnesses to keep their testimony to about 5 minutes, so that we will have an opportunity for questions and answers.

Dr. Kerrigan, we are pleased to have you with us.

STATEMENT OF JAMES P. KERRIGAN, D.D.S., MEMBER, COUNCIL ON LEGISLATION, AMERICAN DENTAL ASSOCIATION, ACCOMPANIED BY HAL CHRISTENSEN, DIRECTOR, WASHINGTON OFFICE

Dr. KERRIGAN. Mr. Chairman and members of the subcommittee, I am Dr. James P. Kerrigan of Washington, D.C.

Accompanying me is Mr. Hal Christensen, director of the ADA Washington office.

I am a member of the Council on Legislation of the American Dental Association, and am pleased to have this opportunity to present the views of that organization on the various child health assurance proposals which are before you.

As I believe this committee is well aware, the American Dental Association has traditionally placed its highest priority on the dental care of children. Development during childhood of effective regimens of diet, professional treatment, and home care is the foundation of a lifetime of sound oral health.

Dental care for the children of indigent families and families that are minimally self sustaining is frequently neglected. This occurs for several reasons, but certainly severely limited finances is a significant factor. Because of this situation, the association has long advocated the inclusion of dental services in health care programs aimed at these children and also has promoted the introduction of separate legislation to the same effect.

The record of last year's hearings before this subcommittee documents the association's longstanding support of efforts to improve medicaid coverage of dental care for needy children. This includes the association's original and continuing support for the intent and purpose of the existing early and periodic screening, diagnosis and

treatment program as a mechanism for addressing the dental and overall health care needs of low-income children covered by medic-aid. Unfortunately, as the bills before this committee recognize, that program has not been effective in meeting the needs of poor children particularly with respect to dental services.

Included in the regulations promulgated under EPSDT is a requirement that each State provide "at least such dental care as is necessary for relief of pain and infection and for restorations of teeth and maintenance of dental health" (CFR 239.10(b)(3)(IV)).

While this would appear to be a clearcut directive and commitment to the States, for one reason or another its implementation has been far less than satisfactory in assuring the availability of needed dental care for eligible children.

Statistics compiled by the Congressional Budget Office indicate, for example, that only 25 percent of the children who are screened may actually be referred for dental care because some States are reluctant to find dental problems they would be required to treat. Even this statistic is somewhat misleading, in that only 2 million of the approximately 11 million children who are eligible for EPSDT are screened.

The other compelling statistics are that only 40 percent of children under the age of 18 who are from low-income families have ever been to a dentist and that 97 percent of such children have been found to require some dental care before the age of 6. The need is clearly there. An improved mechanism for adequately addressing that need must be developed. We believe this can be done through the CHAP legislation which is before you.

I would now like to address several of the major provisions of these bills.

Dental benefits: Each of the bills before you recognizes the necessity for providing dental care to children by mandating this care as a medicaid benefit for low income children and by including dental care as a CHAP benefit. We are pleased that none of the proposals would require a dental screening prior to allowing a child to receive needed dental care.

As we have stated, the extent of need is so predictable among these poor children that an initial screening step is simply unnecessary and therefore not cost effective. Direct referral to a dentist as provided under H.R. 2461 and H.R. 4053 and, as we understand, intended in H.R. 2159 is the most effective manner for assuring the availability of necessary care.

In this regard, although the administration bill, H.R. 4053, would require that referral and a list of dentists participating in the CHAP program be provided each eligible child, there is no requirement that followup be provided. This is an important omission since the performance standards and enforcement provisions do not apply to the delivery of dental care. In other words, although dental care would be a required health care service under CHAP, there would be no way to insure that children nominally referred to a dentist would actually go and receive necessary treatment.

Without adequate followup for dental referrals, it is very possible that few children will actually see a dentist. Thus, the association supports the provision in H.R. 2159 which would require the health

care provider, or State agency, to be responsible for following up on referrals to assure the proper provision of treatment.

In addition, we support the provision in H.R. 2159 and H.R. 2461 requiring a list of dentists located in the same area as the health care provider. The administration bill impractically requires a list of CHAP dentists in the whole State.

Federal matching assistance: We favor the provisions of H.R. 2159 and H.R. 2461 relating to the Federal level of matching assistance for care provided under CHAP. We believe it is important that there be a significant increase in Federal incentives and that the increase be definite in amount in order to allow the States to appropriately plan and carry out this program. These two bills meet both objectives although the actual levels of assistance would differ somewhat.

H.R. 4053, on the other hand, would appear to give the States an indefinite commitment of matching support based upon an after-the-fact evaluation of compliance with performance standards. It would seem to us that in order for the program to be successful the States should know with certainty from the outset the specific level of matching funds that will be provided for the services to be delivered. In other words, it is our opinion that bonuses or penalties based upon performance standards should relate to administrative efficiencies or deficiencies and should not reduce the funds available for the care of needy beneficiaries.

We note that both H.R. 2159 and H.R. 2461 would establish two levels of Federal matching assistance for dental care based on whether or not a child has previously received an assessment. As indicated previously a major concern of the dental profession is that all medicaid children be eligible for dental care whether or not they have been assessed.

These provisions accomplish that goal and provide needed incentives to bring children into the overall assessment process. We would suggest that as one mechanism for simplifying administrative responsibilities all dental care provided to eligible children be matched by the Federal Government at the higher CHAP percentage, with the added requirement that each dentist inquire as to whether or not a child has been assessed.

If the child has not been assessed the dentist would so inform the State agency. This approach would utilize an additional possible point of entry into the health care system, the dentist, as a source of assuring that eligible children receive assessments. In addition, it will provide needed added emphasis on the importance of dental care and should provide a needed incentive to the States to carry out appropriate dental care programs.

Provided participation: Successful implementation of the EPSDT program has been hindered by the series of burdens placed upon practitioners who are willing and able to participate in the program.

One of these, of course, is the generally inadequate level of reimbursement provided under the medicaid program in the various States. Another is the often inordinate delay in receiving reimbursement. Added to these, of course, are excessive paperwork and other questionable requirements. While all of these problems cannot be eliminated.

It is in all of our best interests and particularly the interests of the beneficiaries that such burdens be kept to the absolute minimum consistent with reasonable accountability. We are pleased with the provision in H.R. 2461 which seeks to attract sufficient participating practitioners to render the required services particularly through reasonable reimbursement levels and prompt payment.

In summary, while all three bills are well intended, the indefinite nature of many of the major provisions of the administration bill could result in a program which is no better and perhaps a step backward from the current EPSDT program with respect to the provision of dental care for poor children. We believe H.R. 2159 and H.R. 2461 would establish a much more effective basis for a successful program to replace EPSDT.

As a final comment, I would emphasize again that the investment we can make in the children covered by this legislation will bring them greatly improved health for their lifetimes and will save untold millions of dollars in health care costs in the future.

Mr. Chairman, on behalf of the ADA I wish to personally thank you, Representatives Carter and Maguire, and the other members of this subcommittee, for the very diligent efforts you have made on behalf of this legislation.

Mr. WAXMAN. Thank you very much.

Dr. Carter?

Mr. CARTER. Thank you, Mr. Chairman.

I certainly want to welcome you here this morning.

I appreciate your presentation very much, and I am glad to see you, Mr. Christensen.

Years ago I learned the dental handshake from a friend of mine. Always when I shake hands with a dentist he goes like this: This is the way he loosens the tooth, you know. He gets so used to that that he can only shake hands that way.

Do you feel, Doctor, there should be limitations placed on the amount, duration, and scope of routine dental services?

Dr. KERRIGAN. Dr. Carter, what kinds of limitations are you referring to?

Mr. CARTER. Well, orthodontia, to include that.

Dr. KERRIGAN. Being an orthodontist I can address that point very well.

There are what we call severely handicapping malocclusions. These children many times have a warped life, and for the severely handicapping ones, I think we can provide adequate indices that the Secretary could use; there are mechanisms providing for effective screening so that only the really handicapped would receive those benefits.

Mr. CARTER. Yes. There are some cases actually in addition to malocclusion; you have psychiatric effects from projecting teeth, things of this nature; is that correct?

Dr. KERRIGAN. Yes, sir, in fact there is a Dr. Charles Tweed who was an eminent leader in the orthodontic field who said many times a patient can live a normal life with an abnormal bite but he can't live a normal life with an abnormal face.

Mr. CARTER. They feel it and know it, too.

Dr. KERRIGAN. Yes, sir.

Mr. CARTER. How should limitations be established or should there be any limitations on the treatment?

Dr. KERRIGAN. I happen to be on a National Academy of Science Committee in which we addressed ourselves to this particular thing. It was funded by the U.S. Army in which we tried to set up various indices so that these problems could be assessed, and they were assessed on a functional basis, the actual anatomical basis and psychological basis.

There are a number of indices which have already been established which could be used to properly screen so that only the truly deserving would receive those benefits.

Mr. CARTER. Yes. The administration bill excludes orthodontia. We have been over there, I believe.

Dr. KERRIGAN. Yes, sir.

Mr. CARTER. Are there adequate numbers of dentists who participate in the CHAP program?

Dr. KERRIGAN. I think perhaps in the past the amount of participation on behalf of the general dentists in the communities has been lacking, and the reasons for it have been administrative routines which are so cumbersome.

Among other reasons was the fact that when reimbursements were forthcoming, there were long delays, and last but still very important is that the level of reimbursements are totally inadequate.

Mr. CARTER. Yes.

We certainly hope to remedy that in this program.

Do you anticipate that there will be many dentists who would refuse patients?

Dr. KERRIGAN. I would think any conscientious dentist would not refuse a patient.

Mr. CARTER. I certainly agree with that and say that for the physicians also.

Dr. KERRIGAN. Right.

We would be only too happy to solicit our membership that they would fully comply in any area and on any basis reasonably possible.

Mr. CARTER. Yes.

Dr. KERRIGAN. That happens to be, of course, a leadership role for the American Dental Association. I think there would be no problem in actually getting an adequate number of private practitioners to help these needy children.

Mr. CARTER. Yes, sir.

Thank you very kindly, Doctor.

Dr. KERRIGAN. Thank you, Dr. Carter.

Mr. WAXMAN. Thank you, Dr. Carter.

Mr. Maguire?

Mr. MAGUIRE. Thank you, Mr. Chairman.

Doctor, what do you think has been the major barrier to providing needed dental services to poor children in the past?

Dr. KERRIGAN. I think actually it's an educational process. There are several innovative programs going on in California now where they are starting to teach health as a course throughout each year, throughout the primary grades. So I think it's a matter of education.

I think it's also a matter of behavior and, of course, there are cost factors too. But I certainly would like to see some way that we could break through to really help this Nation preserve its greatest asset, and that is the health of its citizens and, of course, that starts with the children.

Mr. CHRISTENSEN. Could I add to that?

I believe one of the biggest problems, I don't believe it, I know it, has been the failure of the States to cover dental care within their programs even with the EPSDT, which appears to mandate it. The Federal Government has not enforced the requirement, and not only that, dental care has been the first to be reduced or eliminated whenever a State has a budget problem.

So I think a major problem that we can't overlook and one that your bill and the others here address is making it a requirement that the States do provide this care.

Mr. MAGUIRE. You have a keen interest in providing care for those children that already have dental problems. What can you tell us about programs for preventing dental disease, educational materials, to help families work on preventing dental disease and ways of getting information to the children themselves?

Are these areas that you have been concerned with, areas you have taken an interest in?

Dr. KERRIGAN. We are always concerned. We would also like to see dental fluoridation. In other words, dental health education is something that the dental profession has long advocated so very strongly because this is, I believe, the second greatest public health effort in the accomplishment of our purpose, second only to the effectiveness of water fluoridation and this is one area where it could be started.

I believe that there is a wonderful program, a real place for the Federal Government to actually try to get some of these educational programs operations by funding them in the schools. I don't think they should be carried on solely by the professionals, the dentists themselves.

I think there should be a special type of health care teacher that can come in, somebody who can motivate them perhaps on their own peer level, but prevention is the answer. It certainly isn't treatment or cure.

Mr. MAGUIRE. Don't dentists have to participate in the initiative?

Dr. KERRIGAN. Dentists would participate in setting up the programs and leading them in any way. We have a bureau, a council in ADA that addresses itself continuously to that type of program and problem.

Mr. MAGUIRE. Another area of concern is followup. You have indicated that in your statement, and also have mentioned problems with referral. I think sometimes one of the problems is a lack of coordination between dental care and general health care services.

I wonder if you have any suggestions how to link the two up effectively.

Dr. KERRIGAN. I think as provided in your bill and Dr. Carter's bill it says it would become a responsibility now of the State agencies. Sometimes in trying to turn these types of responsibilities over to the primary health care provider he becomes so inundated

with the paperwork that sometimes he may not be as forceful as possible.

I don't know quite what the answer is but I think certainly having a requirement for funding perhaps will make the States do a better job in that respect.

Mr. CHRISTENSEN. One of the suggestions we make in our statement in that regard is, since your bill and Dr. Carter's bill provide for the direct referral, regardless of the CHAP assessment, we think it would be reasonable to expand that effort by having the dentist go back to the State agencies, too, whenever he has a poor child who comes to his office who hasn't been through the assessment program, he would refer that child into an assessment program, as well as the other way around.

That would provide a new portal of entry which I think would be an improvement in the bill. That is one way of helping with the objective you are talking about.

Dr. KERRIGAN. In the private practice sector, Congressman, we have a routine recall system and perhaps if something could be built in on that, because certainly prevention is based on periodic screening or periodic care, I think that would be an effective step.

Mr. MAGUIRE. Thank you very much, gentlemen.

I appreciate your statement and your leadership in this area, which I think is very important.

Dr. KERRIGAN. Thank you.

Mr. WAXMAN. We thank you very much for your testimony. Let me ask you one quick question.

In California—you may not be familiar with this, Dr. Kerrigan—but in California the State has made arrangements with the Delta Dental Plan for provision of dental service to the medicaid population. They believe it to be cost effective.

I would like your comments on that arrangement. Should we add provisions to the CHAP bill to encourage States to enter similar arrangements with dental plans or other organizations of dentists?

Dr. KERRIGAN. I would say anything that is effective we would certainly support, and I would say that is probably a step forward.

Mr. CHRISTENSEN. Could I add to that?

It's my understanding of that California plan that it's a very effective program and in particular it enlists the cooperation of all the dentists who are already participants in that program, and that is most of the dentists in California. Under that system, right off the bat you have licked the participation problem. And, I think the California experience will show that it has been more cost effective than when the State was running it through its own administration.

Mr. WAXMAN. Dr. Kerrigan, you mentioned in your testimony that the American Dental Association favors the provision in the bill which would require a primary health care provider to make a referral to a participating dentist.

I am concerned, however, that in many areas where participation of dentists in medicaid is low we would be asking physicians or other primary providers to make referral when it would be difficult for them to do so.

I would like your comments on that and what is the ADA doing to encourage greater participation by dentists in medicaid? I know

you have been asked that same question by Dr. Carter. I would like to hear your views on it.

Dr. KERRIGAN. Well, of course, we promote a National Dental Health Day every year, and throughout, all our legislative efforts we primarily have been trying to take care of the children. I would think that perhaps if there were any areas where deficiencies were brought to the attention of the local ADA component or to the attention of us nationally, we would see to it that the local component society or constituent society in that State will address itself to the problem. I feel sure you won't find that our cooperation will be lacking.

Mr. CHRISTENSEN. Could I add one comment?

We are in the process of developing, or improving on, I should say, a national access program which we hope to refine on somewhat of a crash basis, but there is no question but what the American Dental Association will do everything in its power to induce its members to participate in the program. I think it can be successful provided the Federal Government will live up to its responsibility in behalf of the poor.

Mr. WAXMAN. Thank you.

Any other questions?

Your testimony has been very helpful and we appreciate your views and certainly are going to take them into consideration in these hearings

You have been a strong supporter of the legislation and we appreciate your efforts.

Mr. CHRISTENSEN. Thank you very much.

Dr. KERRIGAN. Thank you very much.

Mr. WAXMAN. We will now call Jewel Hamilton, Child Health Assurance Program Coalition, accompanied by Mary Akerley, director, National Society of Autistic Children, and Chris Koyaragi, special consultant, National Council of Community Mental Health Centers.

Mr. CARTER. Mr. Chairman, I want to welcome Mrs. Hamilton here today; I have known her for many years. She was prominent in Kentucky and in this very field. She lived there for many years, although she is a native of Texas. I believe she has three brothers who are physicians in Kentucky.

Mrs. HAMILTON. Right.

Mr. CARTER. They helped me in time of great stress, and I personally want to welcome her here today.

Mrs. HAMILTON. Thank you very much.

Mr. WAXMAN. Thank you.

STATEMENT OF JEWEL HAMILTON, ON BEHALF OF DEVELOPMENT DISABILITIES/MENTAL HEALTH CHAP COALITION, ACCOMPANIED BY MARY AKERLEY, DIRECTOR, NATIONAL SOCIETY OF AUTISTIC CHILDREN, AND CHRIS KOYARAGI, SPECIAL CONSULTANT, NATIONAL COUNCIL OF COMMUNITY MENTAL HEALTH CENTERS

Mrs. HAMILTON. Thank you, Mr. Chairman.

My name is Jewel Hamilton from Texas, I am the immediate past executive secretary for the General Federation of Women's Clubs and am presently a committee chairwoman on the task force

to implement the recommendations of the congressionally mandated Commission for the Control of Epilepsy and its consequences.

I have been concerned about the needs of our children, especially children with developmental disabilities, for many years. As chairwoman for the Kentucky Commission on Children and Youth and a member of the Advisory Board for the White House Conference on Children and Youth, I worked very hard to assure that all children had an equal opportunity to grow up to be healthy, productive citizens.

Throughout my 31 years of volunteer activity, I have always maintained a very special concern for our handicapped children. In fact, I served as the chairwoman for the National Advisory Council on Developmental disabilities.

Today, at the invitation of the Epilepsy Foundation of America, I am representing a coalition of 14 developmental disability and mental health groups. These groups have been working for more than a year in an ad hoc CHAP coalition of over 20 organizations to improve health and mental health care for our low income children.

As a coalition, we support full and equal coverage for mentally ill and developmentally disabled children. We are opposed to limitations in the administration's bill on the amount, duration and scope of health and mental health services including inpatient services.

We recommend to you, Mr. Chairman, that the committee approve unlimited coverage for services furnished in community mental health centers and other organized care settings. We wish to submit for the record information on the mental health needs of children and recommendations to meet them as part "B" of our statement. [See p. 204.]

My interest in providing all disabled children with care and services is not new. In the Governor's office in Kentucky, I worked for passage of legislation to guarantee that handicapped children would receive appropriate education and services. I firmly believe that our children are our greatest resource. It is important that we as a society insure that mentally and physically disabled children are provided with the kinds of health and mental health treatment they so desperately need.

I would like to take a few minutes to discuss the very special problems of developmentally disabled children. These are the children who are severely handicapped early in life; their disabilities rob them of a normal developmental experience and cannot be cured. Examples of such disabilities are autism, cerebral palsy, epilepsy and mental retardation.

It has been well documented that disabling conditions occur more often among the low income population medicaid, and EPSDT, is designed to serve. Such conditions often first appear during infancy or the preschool years. Without immediate and ongoing care, these conditions can become permanently disabling. Early intervention and followup can prevent the development of some forms of disability, such as mental retardation caused by inborn errors of metabolism, can dramatically reduce the severity of the disability, as in many disorders which if untreated, can significantly increase in frequency and intensity of occurrence, can

compensate for disability produced impairments as in the case of children with cerebral palsy who, with appropriate therapy can be helped to reduce or compensate for communication and motor difficulties, and can reverse symptoms, as in the case of those autistic children whose cognitive and behavioral functioning has improved significantly as a result of neurological intervention.

Unfortunately, the few Federal programs providing some medical or health related services to children with developmental disabilities are so fragmented, condition/region specific, and hedged with varying eligibility requirements and applications procedures that tracking services becomes confusing and frustrating. It almost goes without saying that under these conditions continuity of services is impossible to guarantee.

In our written testimony we have cited several examples of programs which make it difficult for disabled children to obtain necessary services. However, I would like to point out, that even when services are available, disabled children, because of the very nature of their handicaps, often have difficulty accessing them. Something as comparatively simple as routine dental care can become expensive and complex if the child is retarded and needs patient, careful preparation by the dentist before his teeth can be cleaned and checked.

Dental treatment for a hyperactive autistic child or for a youngster with cerebral palsy who cannot control his head and body movements may be possible only under general anesthesia. If providers are not going to be compensated for the extra work involved, they, with rare exceptions, are not going to treat these children. It appears to us that the incentives in the administration's bill come closest to taking these factors into account.

Of all child population groups, low income children are at greatest risk of experiencing developmental disability or delay as the result of inadequate prenatal care. Therefore, we endorse the CHAP proposal to include coverage for pregnant women. Teenage pregnancies in particular present a growing concern since children from such pregnancies have a greater chance of developing a handicapping condition. For example, it is a fact that the number of mentally retarded children born to teenage mothers is 17 times higher than the national average.

One of our biggest concerns, Mr. Chairman, is that CHAP provide disabled children with all kinds of services they need. Both the McGuire-Waxman and Dr. Carter's CHAP proposal require that a broader range of medicaid services be made available to eligible children. The administration, on the other hand, has expanded the services CHAP will cover, but fails to provide for many optional medicaid services. We have attached a chart [see p. 203] to the testimony showing which optional services States covered in 1978.

For a developmentally disabled child, services such as physical or speech therapy, orthopedic devices, mental health services and other screening, preventative diagnostic and rehabilitative services are essential to his or her health and well-being. However, many States do not cover these optional services or cover only a few of them.

Let me give you an example. It is estimated that nearly three-fourths of the persons with epilepsy have multiple handicaps. This

means, that in many cases, bringing a child's seizures under control will only solve half the problems if other services such as speech therapy or rehabilitative programs are unavailable. Moreover, it does not make sense to provide a child with cerebral palsy or other crippling conditions with basic health and dental care while ignoring his or her need for physical therapy.

In addition to insuring that all necessary health services are made available to children, both H.R. 2461 and H.R. 2591 remove limitations on the amount, duration and scope of such services.

Important to note, that while developmentally disabled children share the same needs for basic health care as other children, in some cases, their special problems require more intensive or prolonged treatment. For example, a child with epilepsy may need two or more types of drugs to control his or her seizures. The cost of his medication can be as high as \$1,300 a year. However, some States limit payment for drugs to \$20 a month and restrict the types of drugs available.

To allow limits to be placed on the delivery of health services undermines the receipt of necessary care and virtually assures that the children who need services the most will suffer.

Another issue of concern to us, Mr. Chairman, is the proposed limit on inpatient care. We would like to point out that the majority of mentally retarded and mentally ill children do not require costly, long term inpatient care. For most, no inpatient services are required, for others, structured 24-hour intervention for a period of time, not lifelong, can mean the difference between being able to function in the community and being relegated to custodial care in an institution—another instance of when the costs of saving money are incalculably high.

Let me give you just one example of this problem. Zandy, a youngster with autism, was in a 24-hour program in a nearby State. Zandy's program was only partially paid for with public money, the education component was covered by State and Federal funds, but not the medical costs. His parents had health insurance but like most policies, its mental health coverage was limited. They were billed for the difference, could not pay it all, and ran up a debt of several thousand dollars. Zandy was transferred to a less costly and much less appropriate facility. His new program was for less handicapped children, its staff/patient ratio was too low and its program inadequate. Within a month Zandy was dead. He had wandered away into a nearby woods during an outdoor playtime. Autistic children are notorious for their ability to disappear unnoticed and walk for miles, and after 2 days of wandering he became mired in a muddy swamp where he died.

The provisions in the McGuire-Waxman bill would prevent this type of tragedy and we therefore urge the subcommittee to adopt that language for inpatient care.

At this point, I would like to note we have a number of other concerns relating to assessment and various administrative provisions that are elaborated in our written statement.

[Testimony resumes on p. 214.]

[Mrs. Hamilton's prepared statement and attachments follow:]

TESTIMONY ON THE CHILD HEALTH ASSESSMENT PROGRAM

(H.R. 2159, H.R. 2461, H.R. 4053)

Presented to the Subcommittee on
Health & the Environment

House Committee on Interstate and Foreign Commerce

June 11, 1979

Presented By

Jewel Hamilton

on behalf of

THE DD/MENTAL HEALTH CHAP COALITION

Developmental Disabilities
Organizations

Epilepsy Foundation of
America

National Association for
Retarded Citizens

National Association of
State Mental Retardation
Program Directors, Inc.

National Easter Seal
Society for Crippled
Children and Adults

National Society for
Autistic Children

United Cerebral Palsy
Association

Mental Health Organizations

American Association for the
Advancement of Psychology

American Association of
Children's Residential
Centers

American Association of
Psychiatric Services for
Children

Mental Health Association

National Association of
Private Psychiatric
Hospitals

National Association of
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National Council of Community
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National Congress of Parents
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Mr. Chairman, I am Jewel Hamilton from Houston, Texas. I am the immediate past Executive Secretary for the General Federation of Women's Clubs and am presently a committee Chairwoman on the Task Force to implement the recommendations of the Congressionally mandated Commission for the Control of Epilepsy and its consequences.

I have been concerned about the needs of our children, especially children with developmental disabilities, for many years. As Chairwoman for the Kentucky Commission on Children and Youth and a member of the Advisory Board for the White House Conference on Children and Youth, I worked very hard to assure that all children had an equal opportunity to grow up to be healthy, productive citizens.

Throughout my 31 years of volunteer activity, I have always maintained a very special concern for our handicapped children. In fact, I served as the Chairwoman for the National Advisory Council on Developmental Disabilities.

Today, at the invitation of the Epilepsy Foundation of America, I am representing a coalition of Developmental Disability and Mental Health groups. These groups have been working for more than a year in an ad hoc CHAP coalition to improve health and mental health care for our low-income children.

As a coalition, we support full and equal coverage for mentally ill and developmentally disabled children. We are opposed to limitations in the Administration's bill on the amount, duration, and scope of health and mental health services including inpatient services.

We recommend to you, Mr. Chairman, that the Committee approve unlimited coverage for services furnished in community mental health centers and other organized care settings. In addition, we support provisions to require HEW to ensure adequate reimbursement rates for qualified providers of health care services including mental health.

My interest in providing all disabled children with care and services is not new. In the Governor's office in Kentucky, I worked for passage of legislation to guarantee that handicapped children would

receive appropriate education and other services. I firmly believe that our children are our greatest resource. It is important that we as a society ensure that mentally and physically disabled children are provided with the kinds of health and mental health treatment they so desperately need.

I would like to take a few minutes to discuss the very special problems of developmentally disabled children. These are children who are severely handicapped early in life; their disabilities rob them of a normal developmental experience and cannot be cured. Examples of such disabilities are: autism, cerebral palsy, epilepsy, and mental retardation.

PART A

SERVICE/ELIGIBILITY CONCERNS

It has been abundantly documented that disabling conditions occur with greater frequency among the low-income population which Medicaid is designed to serve. Such conditions often first manifest themselves during infancy or the preschool years. Without immediate and ongoing therapeutic intervention, these conditions can become permanently disabling. With many low-income children in need of treatment for medical conditions related specifically to problems of growth and development, it becomes particularly essential that individuals so identified be eligible to receive the full range of screening, referral, treatment, and follow-up services available under Medicaid auspices, so as to ensure the amelioration of their condition before damage or degeneration becomes irreversible.

Early intervention and follow-up can prevent the development of some forms of developmental disability (such as mental retardation caused by inborn errors of metabolism); can dramatically reduce the severity of the disability (as in many seizure disorders which, if untreated, can significantly increase in frequency and intensity of occurrence); can compensate for disability-produced impairments (as in the case of children with cerebral palsy who, with appropriate therapy, can be helped to reduce or compensate for communication and motor difficulties); and can reverse symptoms (as in the case of those autistic children whose cognitive and behavioral functioning has improved significantly as a result of neurological intervention).

Unfortunately, the few federal programs providing some medical or health-related services to children with mental retardation and developmental disabilities are so fragmented, condition/region specific, and hedged with varying eligibility requirements and application procedures that tracking appropriate services within such a "non-system" becomes a confusing and frustrating process; and it goes almost without saying that under these conditions continuity of services is impossible to guarantee.

Crippled Children's Services are a case in point. States must provide evaluations but may select which services they will provide and which disabilities they will cover. For example, some states have elected to restrict the type and duration of restorative services they will provide for mentally impaired children, even though those children may be eligible because of a physical handicap. Then there is the additional restriction of income eligibility, which varies from state to state. In our mobile society, it is well within the realm of probability that a child receiving needed care could, by virtue of his family's moving to another state, lose all those medical services even though the family's income remained the same.

Another example of our half-hearted approach to health care are the restrictions written into section 1615B of Title XVI. The intent of the program, to habilitate low-income disabled children, is excellent; however, services (medical and habilitative) are limited to SSI children six years old and younger (with some exceptions) on the assumption that children above that age are in school and therefore fully served. Yet, the regulations for P.L. 94-142 specifically prohibit the provision of medical services with education dollars. These services are also reserved for children who will have the best chance as self-sufficiency as adults; translated, that of course means the least impaired. In our legislating for human need, we have acquired a remarkable ability to disqualify those most in need, while giving the appearance of responsible beneficence.

Part of the problem is that we are not fully comfortable with spending monies from one pot to reduce expenditures from another. Many children with epilepsy could attend regular school, thus saving thousands of education dollars per child, if their seizures were controlled through the expenditure of relatively modest amounts of health dollars. Yet, when a state does not cover prescription drugs, or requires a co-payment for them, or discontinues payment due to a modest increase in the family's income or -- worse yet -- because the seizures are controlled,

it believes it is saving money. No one ever seems to look beyond his immediate area of responsibility to assess the real costs of an apparent "saving."

Even when services are available, DD children, because of the very nature of their handicaps, often have difficulty accessing them. Something as comparatively simple as routine dental care can become expensive and complex if the child is retarded and needs patient, careful preparation by the dentist before his teeth can be cleaned and checked. If, because of his retardation, routine oral hygiene is deficient, that cleaning can take longer; yet the dentist cannot bill Medicaid (or anyone else) for the extra time. Dental treatment for a hyperactive autistic child or for a youngster with cerebral palsy who cannot control his head and body movements may be possible only under general anesthesia. If providers are not going to be compensated for the extra work involved, they, with rare exceptions, are not going to treat these children. It appears to us that the incentives in the Administration's bill come closest to taking these factors into account. We will address this aspect of the legislation more specifically later in our testimony.

Of all child population groups, low-income children are at greatest risk of experiencing developmental disability or delay as the result of inadequate prenatal care, poor nutrition, environmental hazards such as lead-based paint poisoning and mercury toxicity, and above all, lack of or insufficient use of health services.

We endorse the CHAP proposal to include coverage for pregnant women. HEW estimates that some 25,000 women with incomes below the poverty level are not covered by Medicaid. The chances are good that these women are not receiving adequate prenatal care. Injury, infection, or systemic illness of the mother during pregnancy can cause an otherwise healthy baby to be born disabled. In addition, teenage pregnancies present a growing concern since children from such pregnancies have a greater chance of developing a handicapping condition. For example, it is a fact that the number of mentally retarded children born to teenage mothers is seventeen times as high as the national average. Adequate

medical care during pregnancy can prevent needless disability. Moreover, it is important that this most basic aspect of prevention, good prenatal care, be available to all low-income women regardless of their family structure or the fact that it is their first pregnancy.

We are pleased that the Administration's CHAP proposal has expanded the number of services covered by Medicaid for eligible children by including prescription drugs, immunizations, vision and hearing services and dental care. However, unlike the other two CHAP proposals, the Administration's bill fails to mandate coverage of other optional Medicaid services that are essential for a developmentally disabled child.

We would like to emphasize that many of the health services needed by a developmentally disabled child may not be included under a state's Medicaid plan. In fact, many states have chosen not to cover these "optional" services or cover only a few of them. Moreover, the availability of health service varies considerably from state to state. We have attached a chart to this statement showing which optional services states covered in 1978. As you can see, there is a considerable disparity between the types of services offered in each state.

Both H.R. 2591 and H.R. 2461 require that a broader range of Medicaid services be made available to eligible children. For a developmentally disabled child, services such as physical or speech therapy, orthopedic devices, mental health services and other screening, preventive, diagnostic and rehabilitative services are essential to his or her health and well being. For example, it is estimated that almost three-fourths of the persons with epilepsy have multiple handicaps. This means, that in many cases, bringing a child's seizures under control will only solve half the problem if other services such as speech therapy or rehabilitative programs are unavailable. Moreover, it does not make sense to provide a child with cerebral palsy or other crippling conditions with basic health and dental care while ignoring his or her need for physical therapy.

It is important that developmentally disabled children have access to the kinds of medical services that are appropriate to their needs. We therefore encourage that the broadest possible coverage for all eligible children be provided under CHAP.

In addition to ensuring that all necessary health services are made available to disabled children, both H.R. 2461 and H.R. 2591 remove limitations on the amount, duration, and scope of such services. Current regulations state that Medicaid services provided by a state must be sufficient in amount, duration, and scope to reasonably achieve their purpose. In other words, states have been allowed to set certain limits on health services. It is important to note, that while developmentally disabled children share the same needs for basic health care as other children, in many cases, their special problems require more intensive or prolonged treatment. For example, a child with epilepsy may require two or more types of drugs to control his or her seizures. The cost of this medication can range from \$2 to \$1,300 per year. However, some states limit payment for drugs to \$20 per month and restrict the types of drugs available.

To allow limits to be placed on the delivery of health services undermines the receipt of necessary care and virtually assures that the children who need services the most will be made to suffer.

We are adamantly opposed to a limitation on inpatient care, and we must question whether basing that limitation on a specific handicap (mental illness or mental retardation) is not in fact a violation of section 504 of Title V of the Rehabilitation Act? Once again, we realize the motivation is to limit costs; but we would like to point out that the majority of mentally retarded and mentally ill children do not require costly, long-term, inpatient care. For most, no inpatient services are required; for others, structured, twenty-four hour intervention for a period of a year or two (not a lifetime) can mean the difference between being able to function in the community and being relegated to custodial care in an institution -- another instance of when the costs of "saving" money are incalculably high.

Let me give you an example. Zandy, a youngster with autism, was in a twenty-four hour program in a near-by state. We are not identifying the state because its service problems are not unique to it, nor are they entirely its fault. We have, however, used the child's real name, because he's dead now and society can do him no further harm.

Zandy's program was only partially paid for with public money; the education component was covered by state and federal funds, but not the medical costs (remember the 94-142 prohibition). His parents had health insurance, but like most policies, its mental health coverage was limited. They were billed for the difference, could not pay it all, and ran up a debt to the state of several thousand dollars. Zandy was transferred to a less costly, and much less appropriate facility. His new program was for less handicapped children; its staff/patient ratio was too low and its program totally inadequate. Within a month, Zandy was dead. He had wandered away into a near-by woods during an outdoor play-time (autistic children are notorious for their ability to disappear unnoticed and walk for miles); after two days of wandering, he became mired in a muddy swamp where, after another twenty-four hours of misery, he died -- not of suffocation, but exposure.

Perhaps we have picked a poor example. Zandy's parents paid for his funeral, and he's not going to cost the world another penny; so money has truly been saved through the withholding of a needed service. However, none of us believe that killing kids is an appropriate means of cost containment. The provisions of the Maguire-Waxman bill (H.R. 2461) would prevent this type of tragedy, and we urge the Subcommittee to adopt that language for inpatient care.

We would like to note that the Administration's CHAP proposal had eliminated a significant barrier to the receipt of services for all children, including the developmentally disabled. The Administration's bill would allow eligible children to receive certain health services regardless of whether or not the child had gotten a formal health assessment. Since only a fraction of the eligible children are being assessed

through the EPSDT program, many are not receiving preventative or routine health care. It is important that children not be required to wait for a health assessment before seeking health or dental services. The requirement that a child receive a formal assessment prior to receiving care virtually assures that there will be a significant gap between the onset of the illness or disability and treatment. Moreover, such delays can aggravate the condition and increase the likelihood that the child will not be returned for treatment at all.

ADMINISTRATIVE CONCERNS

Only about one-quarter of the eligible children are screened under the EPSDT program. We believe that effective outreach is essential if CHAP is to actually reach the women and children it is designed to serve. Increasing the Federal share of outreach costs will offer states an incentive to develop outreach programs. However, certain minimal guarantees are necessary to ensure that states design and implement effective outreach programs. States need to be required by law to identify and provide treatment for a reasonable proportion of the eligible women and children in their jurisdiction.

First, we encourage more effective utilization of the present service delivery system with stronger requirements for individual personal contact. In his testimony before this Subcommittee last month, Secretary Califano announced that, beginning immediately, eligible children identified in other health, education, and welfare programs would be automatically enrolled in EPSDT. We believe this approach should be incorporated as a mandatory provision of whatever CHAP legislation is enacted.

Second, we encourage the use of non-profit community based organizations for the provision of outreach and follow up services. Community organizations often have established information networks that are familiar and comfortable to neighborhood residents. Such organizations can be an invaluable resource for informing and inducing families to take advantage of CHAP services. Moreover, the use of community based

organizations offers a desirable alternative to strict reliance on large, distant, and often impersonal state and/or welfare agencies for providing families with information about CHAP and assuring that these families do in fact receive services.

We enthusiastically endorse provisions in the CHAP legislation that would strengthen state planning requirements by providing for substantial public input in the development of the state plan. Advocates for developmentally disabled children, both parents and professionals, should be encouraged to become part of the planning process for CHAP services. These individuals are a valuable resource for informing the community about the availability of CHAP services. In addition, parents and professionals who understand the special needs of disabled children will help ensure that a state develops and effectively implements a CHAP program that will meet the needs of developmentally disabled children. For these reasons, we strongly support the state plan requirements in H.R. 2461.

Because states, under CHAP, will be required to provide more services (we hope) to more children, it is essential that they receive adequate federal support. We endorse the initial 4 percent increase called for in all three bills and the concept of an increased match based on subsequent performance. However, requirements for maintenance of state effort must be built into the program, so that the increased federal share will not result in the same level of service at less cost to the states. In addition we would, for reasons cited earlier, urge the adoption of the provider incentives provision in H.R. 4053; but suggest that these be made more specific in the legislation itself, rather than left entirely to regulation.

Penalties for non-compliance or substandard performance should penalize the party at fault, not the victim. The Administration's bill would do the latter by withholding service dollars from populations already inadequately served; the state would be no more than a conduit for this inequity. We urge the adoption of the methods called for in Mr. Carter's and Mr. Maguire's bills: a reduction in the federal share

of administrative costs. That, coupled with strong maintenance of effort language, will prevent subversion of the intent of this legislation.

In conclusion, we urge passage of the strongest possible legislation. Even if the initial costs appear high, prevention and good intervention, as early as possible, will reduce the long-term cost to society. Failure to intervene will guarantee the total social and financial dependence of people who could be at least partially self-sufficient as adults, some of them potential taxpayers. Not all of the help they will require as adults is the responsibility of this Subcommittee, but the cost of their programs will fall with equal weight upon the taxpayer, who pays for them without regard to categorical responsibility. The only valid economic principle for CHAP is this: the disability which is prevented costs nothing to treat; the disability which is mitigated costs far less to treat than the one which is ignored. Thank you.

PART B
MENTAL HEALTHMENTAL HEALTH SERVICES UNDER CHAP

Bills pending before the Committee differ somewhat in their coverage of services for mentally ill children eligible under Medicaid and CHAP. The bill introduced by Rep. Maguire and Chairman Waxman, H.R. 2461, is the only bill that provides full coverage for these children. Rep. Tim Lee Carter's bill, H.R. 2159, represents the substantial improvements made by this Committee last year and does mandate ambulatory care with no limitations. We greatly appreciate the introduction of this bill again. The Administration's bill (H.R. 4053) has removed discrimination against mentally ill children but still does not mandate inpatient services in mental hospitals and allows for limits on the amount, duration, and scope of mental health services. We appreciate this move forward but hope that this Committee will go further and adopt the recommendation of the President's Commission on Mental Health to give full and equal coverage to mentally ill children along the lines of H.R. 2461.

As many as 9.6 million children suffer from varying degrees of emotional problems, and less than 10% of children with such problems are receiving adequate help. Three times as many children committed suicide last year as did ten years ago. The U.S. Civil Service Commission on Civil Rights reported that children are receiving mental health services at 1/3 the rate of the 22-44 age group.

In the testimony presented before this Committee on Child Health Oversight on May 16, Mary MacCracken, representing 16 national organizations concerned with developmental disabilities and mental illness, stated:

It is my belief that seriously emotionally disturbed children are not so different from other children. All of us have known fear and loneliness and anger. All of us at times have retreated from reality if only to our television sets -- the difference is in degrees. In these children, illness has magnified their pain and rage a thousand times, and their retreat is often total, out of reality into a world of fantasy, but I believe that if we

could recognize this thread of vulnerability that runs through each of us, we will better understand emotionally disturbed children.

Since children are our greatest resource and our future, the investment needed to mandate a full range of mental health services for children seems small compared to society's costs incurred by children denied early and appropriate screening, diagnosis, and treatment.

The study "Effects of Psychological Treatment on Medical Utilization in Multidisciplinary Health Clinic for Low Income Minority Children," appended to our testimony on May 16, 1979, identified how treatment for mental health problems can significantly reduce medical care utilization costs. This study broke new ground for children as it was in a completely subsidized setting. There was a 36% decrease in the number of medical visits by those children who had an average of 4.9 mental health treatment sessions. The matched control group who received no mental health treatment increased their medical visits by 30%.

Severely disabled children require intensive, and often continuous, skillful care, but early identification and proper remedial treatment can help children less severely afflicted to overcome their problems and live quite normal lives.

The term "mental illness" has different meanings at different times of life. The mental health needs of children differ from those of adults. The diagnostic methods, the training of clinicians, the treatment techniques, the nature of institutional arrangements, and the degree and quality of family involvement necessary for work with children all vary considerably from those treatment patterns appropriate for adults.

The range of mental health disability may be categorized as follows:

Vulnerable children or children "at risk" do not have obvious

psychologic-dysfunction. They have other disabilities often of a chronic character, or they are in family or social settings that require intervention to prevent the development of psychiatric disorder. These children comprise a very large population group and often require intensive and ongoing social interventions to preserve healthy growth and development and to diminish the need for direct psychiatric services later. Some examples of such "at risk" children are the many youngsters with chronic physical disabilities such as blindness, deafness, congenital abnormalities, and the like; children reared in conditions of severe deprivation; children caught up in major natural disasters; children involved in serious parental problems such as alcoholism or bitter custody battles, or loss of a parent through death, desertion or chronic illness, and so forth.

Children with minor and transient evidence of difficulty involving social and emotional elements can usually be managed without psychiatric/psychological diagnosis or treatment. They require help from agencies or other social institutions such as schools, counselors, ministers, Big Brothers, visiting nurses, and the like. Mental health consultation to these agencies and institutions is a valuable source of mental health expertise. Such consultation helps staff in these agencies deal with children with such symptoms and leads to appropriate referrals to mental health treatment when indicated.

Children with evident symptoms of mental or emotional disorder require psychiatric/psychological diagnosis and treatment. The large majority of such children will be adequately served by outpatient treatment. Some will need diagnostic study and evaluation and follow-up interviews. Some may require further regular treatment for 3-6 months. Others may require intensive outpatient treatment from three to four times a week for a period of several years. Special educational study and neurological examination may

also be necessary. The modalities of the required outpatient treatments will vary depending on the individual patient; they may include group, individual and/or family psychotherapy, drug treatment, therapeutic schooling, and others.

A smaller group of children with established psychiatric/psychological diagnoses of mental or emotional disorder will require additional mental health intervention in the form of day hospitalization or day care, therapeutic group homes, therapeutic day nurseries or day schools, specialized half-way houses, or professional foster care placement.

The most disturbed group of children with obvious severe emotional/behavioral disorders of long-standing duration will require highly structured, long-term intensive treatment in the most appropriate inpatient environment. Depending on the individual patient, either a hospital or residential treatment setting will be necessary for adequate care and treatment.

A small number of adolescent patients may require brief hospitalization, residential placement, or day care to help them in dealing with an episode of transient severe mental difficulty, such as attempted suicide. The suicide rate among adolescents has nearly tripled in the past ten years. Following discharge, a further period of outpatient treatment will be required.

Whatever the degree of severity, whatever the modes of treatment, what we are painfully aware of is the fact that without intervention, these children will not be able to grow up to become productive members of society. Without early treatment, such children often do not succeed academically, often drop out of school, and often become a burden within either the social service or juvenile justice system. We cannot begin to estimate the numbers of such children who might have been diverted from years of inappropriate institutionalization or from the criminal justice system if they had

been able to receive early diagnosis and timely care. It should be realized that early and appropriate intervention can preclude the subsequent development of a chronic mental illness. The prevalence of learning disabilities and subsequent academic difficulties are heightened with the presence of untreated mental illness among children.

The concept of early screening diagnosis and treatment is perhaps one of the most cost-effective ways of dealing with the health, both physical and mental, of children. Not only is it less costly to deal with both physical and emotional problems in their early stages, but it is also perhaps one of the best ways to produce healthy adults who can be productive in our society. Failure to provide treatment for the child diagnosed as mentally ill, or developmentally disabled, while saving dollars initially, will clearly cost the Federal government more in the long-run, whether in future, higher health care costs or in social service or juvenile justice system dollars.

Coverage of Ambulatory Services

Of the three major Child Health Assurance Acts pending before this Committee, only Rep. Maguire's H.R. 2461 includes full mental health coverage as recommended by the President's Commission on Mental Health. The Administration proposal, H.R. 4053, is a significant improvement over last year's bill but still excludes inpatient psychiatric benefits for mentally ill children in settings other than general hospitals and discriminates against organized settings in the provision of ambulatory mental health services. Rep. Carter's bill, H.R. 2159, the bill approved by this Committee last year, includes coverage of ambulatory mental health services without limit but does not cover inpatient psychiatric benefits in settings other than general hospitals.

The singling out of mental health clinics in the Administration's bill for limitations on covered services provided to mentally ill children is particularly puzzling. The Federal government has already invested more than \$1.5 billion in the current community mental health center (CMHC) program and in those same centers the state and county governments have invested two billion dollars on top of that. This Administration is currently proposing to initiate a new mental health services program to establish specialized clinics for population groups which are traditionally underserved by mental health agencies and practitioners, including children. Third-party reimbursements, including Medicaid, are critical to the long-term survival of these programs. A recent GAO report^{1/} concluded that "State, local, and third-party revenues (client fees, private insurance, Medicare and Medicaid) must increase so that existing centers may become financially viable."

Existing CMHCs, state and local community based programs, the proposed new agencies, and other mental health service organizations offer many advantages in dealing with the mentally ill child. Through local, state and federal funding, comprehensive services are made available -- including prevention, consultation and education, various ambulatory care services such as emergency, outpatient and partial hospitalization, and inpatient care.

Children with mental health problems were direct recipients of services through state and federally funded community-based programs. The emphasis in community based programs and CMHCs, particularly for children, is on early intervention and treatment. One very effective way to impact upon the mental health of children is through consultation and education programs which through their ties to other agencies in the community -- such as schools, welfare departments, law enforcement agencies, welfare agencies, family services agencies, etc. -- set up a system of care. Children are in fact the primary targets for consultation and education programs in the federally funded

^{1/} Legislative and Administrative Changes Needed in Community Mental Health Centers Program, May 2, 1979, HRD-79-38.

community mental health centers -- 41.1% of all Community Mental Health Center consultations in a sample month in 1977 were with schools and other facilities directly concerned with children.^{2/} Children with minor and transient evidence of difficulty can be helped in this way. Almost all CMHCs and community based programs also include in their education programs classes on parenting and child development.

Family therapy is stressed in CMHC's state and local programs, providing early intervention for the child's mental and emotional problems and enabling the professional not only to help the child, but also to improve the family environment which is often a part of the problem.

Another advantage of covering organized care settings under CHAP, and other Federal legislation, is accessibility. Frequently, community based state and federal programs are the only services available within rural or inner-city areas. To limit services covered in organized care settings further discriminates against those children living in areas with few, if any, readily accessible health services.

Although state and federally-funded community programs provide substantial services to children, there is still a serious shortfall nationwide between the need and the services these programs are able to provide. There are many reasons for this. Some programs have failed to give sufficient attention to the needs of children. Also, there are major resource constraints which hamper efforts of mental health clinics to provide these services. Public programs are unable to attract scarce, specially trained manpower to work in their programs.

Another major constraint is funding -- reimbursement programs, including Medicaid, tend to impact upon the type of service which can be provided. This is particularly true of centers in their last few years of operation under a Federal grant, or whose Federal grant has terminated. These programs become more dependent upon third-party financing and find such financing generally

^{2/}

NIMH Survey and Reports, Provisional Data on Federally Funded CMHCs 1976-1977, May 1978.

available for inpatient services and for a limited amount of outpatient therapy. Under Medicaid, for instance, seven states specifically exclude all clinic services from their Medicaid plans.

Certain mental health services are also often excluded under Medicaid plans, including one which is particularly important for children -- day treatment (excluded in 1975 in Alabama, Maine, Maryland, Virginia and other states). Advance review and approval are sometimes required of mental health services but not of other Medicaid services. Service furnished by non-physician professionals is not reimbursable, sometimes even when furnished under the supervision of physicians.

Coverage of Inpatient Services

The specific exclusion for inpatient psychiatric benefits in settings other than general hospitals continues to be discriminatory, cost-ineffective, and negates concepts of sound quality care.

As CHAP attempts to form a comprehensive delivery system for a specific target population, it should not continue the delivery care patterns of Medicaid. To limit inpatient services to those furnished in general hospitals is to continue care in non-accredited facilities which are neither staffed nor set up to deliver comprehensive services for children or adolescents.

The psychiatric unit of a general hospital is primarily a crisis intervention, short-term stop-gap measure. The per diem rate of that unit runs the same as that of the rest of the hospital -- twice, if not more, that of a specialty facility. The psychiatric unit helps to defray the costs incurred in other units of the hospital. Of the 180-plus private psychiatric hospitals in the country, 165 are short-term acute facilities. The average length of stay is 30.2 days for patients of private psychiatric hospitals.

The length of stay is immediately determined and automatically indicated by the treatment concepts and orientation of the facility.

In the 325 state government mental health facilities, the average length of stay for the 385,000 persons annually in acute treatment (84% of all patients) is 27.3 days. Only 16% of patients in state facilities are long-term care.

On any given day there are 25,000 children and adolescents in state hospitals.

There are 97,000 admissions of children and adolescents to state hospitals each year.

Children are the only age category of patients that went up in "admissions" when measuring last year with 1958. The increase was 86.4%. All other age groups dropped an average of 70%.

The same is true for "resident patients" as for "admissions".

43% of all state-owned-and-operated children treatment programs are accredited by JCAH.

Therefore, we propose that inpatient psychiatric services under CHAP be mandated in any setting which is accredited under the appropriate standards of the Joint Commission on Accreditation of Hospitals (JCAH). Specifically, this would mean that a general hospital offering such services to children or adolescents would be accredited programmatically according to the children and adolescent psychiatric program standards of the JCAH Accreditation Program for Psychiatric Facilities. Similarly, the same criteria would apply to a free-standing psychiatric hospital or residential treatment center for children.

The bottom line is that appropriate accreditation assures sophisticated treatment planning, admission triage, treatment review, discharge planning, and follow-up. This care and treatment should be consistent regardless of setting.

Reimbursements

Under Medicaid, the reimbursement rate for treatment is generally so low that there is no incentive to treat any child and certainly no incentive to treat the emotionally disturbed or developmentally disabled. For example, in 1975, Virginia reimbursed \$7 per hour for group therapy. Many states reimburse clinics at rates substantially below cost. The GAO report cites such problems, including reimbursement rates set ten years ago and never increased. Arbitrary limits are set on the length of treatment, either through limits on numbers of visits or through a total reimbursement limit to any one program.

Recommendations

The proposed CHAP legislation could do much to alleviate these problems and thereby greatly increase access to a full range of mental health services by children of low-income families. The groups supporting this statement urge the Committee to approve legislation which will:

- provide unlimited coverage for state and local community based programs provided in community mental health centers meeting the Federal definition for such centers and for other organized care settings meeting standards prescribed by the Secretary;
- authorize coverage of inpatient psychiatric benefits in accredited mental hospitals and residential treatment centers, as well as in general hospital psychiatric units which have been appropriately accredited;
- provide for HEW to insure realistic Medicaid reimbursement rates for qualified mental health providers.

The children who suffer from mental illness and developmental disabilities have all too often been relegated to second class citizenship in programs in

which children themselves are afterthoughts, appended to larger health programs. The Child Health Assurance Program (CHAP) could provide a first step to ensure that developmentally disabled and mentally ill children do not suffer from discriminatory provisions.

You have the unique opportunity in this International Year of the Child to devise programs that will promote the developmental and mental health of our children today and to prevent and reduce the extent of mental illness and developmental disabilities in the coming century.

Thank you.

Mr. WAXMAN. Thank you very much. That was very useful testimony and I think very much to the point.

Mr. CARTER. Thank you, Mr. Chairman.

Jewel, would you please elaborate on the special problems developmentally disabled children face and the kinds of services they need?

Ms. HAMILTON. I am going to ask Mary Akerley, who is accompanying me today. I would like you to hear from her also.

Ms. AKERLEY. Some of the problems we have that we have touched upon already in our testimony could probably be elaborated on. Let's take the dental care because that was an example in the first testimony this morning.

It costs a lot of money to anesthetize a child so you can clean his teeth, and if that is going to be the necessary procedure to provide a very basic kind of health service, and we have to be prepared, I think, to reimburse providers in a rate compensatory with the amount of time and care they have to give that child. So that would certainly be one example.

Then the kind of half giving of services. Let's talk for a minute about crippled children services because by their very name they are more or less designated for the health care of disabled kids. There are States which limit the amount of restorative services or type that they will provide, not by type of service but by disability, so that if a State elects not to cover mental retardation in its crippled children services plan, even though a child with mental retardation may also have an orthopedic handicap, he or she cannot get the orthopedic related service by virtue you have the mental retardation. It is confusing. It is like for a low income mother trying to get help for a kid. That would be another example of the difficulty our population experiences in getting service.

Mr. CARTER. Thank you. Very interesting.

I understand that the new early and periodic screening, diagnosis and treatment regulations have postponed the requirement that States provide a developmental assessment for disabled children. Specifically, what is a developmental assessment and how does it fit in with CHAP?

Ms. AKERLEY. As you know, Dr. Carter, there are basically now two types of assessments being done with a certain amount of

regulatory or asymetry across the States, and that is physical screening for health needs and dental screening.

The third component which has really been missing since the inception of the program is some assessment how the child is maturing. You might have a child who doesn't have any obvious physical problems, his teeth may be fine but maybe he is not talking, and some sort of sensitive assessment needs to be made of why the child does not talk, perhaps his hearing is impaired, perhaps he is autistic, perhaps he has some degree of mental retardation, perhaps he has a speech defect.

So developmental screening looks at a child in relation of where his peers would be at that point. We are certainly very, very concerned that the administration has dragged its feet on implementing developmental screening. They have never been able to come up with a satisfactory instrument and now if you noted in the regulations, there is some rather dark humor in the language. HEW, in the regulations says we are going to not enforce development screening until January of 1981, in order to give the States a little more time, HEW still hasn't got the guidelines.

Mr. CARTER. I agree with you. It is unusual that they put it off that much longer.

Why are other health programs like the crippled children service not meeting in the health needs of developmentally disabled youngsters?

Ms. AKERLEY. Why are they not?

Mr. CARTER. Yes, ma'am.

Ms. AKERLEY. Partially because of the very eligibility restrictions. We paid some attention a while back—let me backtrack and say a lot of our health care is modeled on the way we treat adults and it hasn't been sensitized to the very specialized needs of kids whether they are disabled or just perfectly ordinary kids.

An example of this is referral for services. If you are an SSI recipient, for quite sometime, even children who are SSI recipients were technically referred to a rehabilitation agency for services if they were on SSI, and then there was an awareness developed this wasn't an appropriate referral for children and we said let's refer them to crippled children services.

Now, there was a feeling, I believe, that was going to cost money, so we have a tendency, I think, in designing programs to really want to help people but to be scared of what it is going to cost you so you try and balance those two things.

What happened with referral of SSI children was that we limited them to children 6 years of age and under, unless they had never been in a public school. Now, there are disabled kids who have a try placement in the public school program and that may be very brief, it doesn't work out and the child is removed and some other setting is designed. But that would, according to the way this particular program is designed, render that child, even if he had only been in the public school a week or two, ineligible for services under that particular program, which says SSI kids are supposed to get health and restorative care.

The other piece of irony in the thing is that the restriction was justified because we said well, children six years and over are in school, Public Law 94-142 is going to meet their needs. Public Law

94-142 is limited by statute and regulation from providing medical services. It is an education bill. So it is a catch-22, isn't it?

Mr. CARTER. Suppose most States had a department of human resources which could assist in keeping the necessary information on each child—especially those eligible under the SSI program and those covered by medicaid. This same department could also help in referring children for proper assessments and treatments.

Do you think that would be a good place for us to keep records of the children who are receiving assessments and treatment or not?

Ms. AKERLEY. I think that would really depend on how well the agency is functioning in the State. And as you pointed out yourself, Dr. Carter, some States don't have those umbrella agencies, so we have a problem, don't we, setting up a nationwide system?

Mr. CARTER. That seems to be one of the big problems to find every one of these children who are eligible and to have a place of keeping their records to see that they get their assessment and their treatments as necessary. What places do you suggest?

Ms. AKERLEY. Well, one of the things that Secretary Califano said when he appeared before this committee last month was that HEW was initiating a program of identifying and referring all of the kids that were EPSDT eligible whether or not they had been formally screened and assessed, identifying them through other kinds of programs. EPSDT is essentially a medical program but an awful lot of children in, say a title I educational program, and those children would be eligible for the service.

Children who are SSI recipients certainly are eligible. Youngsters who are recipients whose families are recipients of AFDC funds and if we looked at all the helping systems and said if I don't catch the kid here I am going to catch him there, the worst thing that could possibly happen is that a child might get referred twice. That seems to me an awful lot better than not being referred at all.

Mr. CARTER. I agree on that.

Thank you.

Mr. WAXMAN. Thank you, Dr. Carter.

Mr. Maguire.

Mr. MAGUIRE. Thank you, Mr. Chairman.

On page 5 of your testimony you say that the administration bill fails to take the special factor relating to development disability into account. Using the example that you have used orally a moment ago about the child with cerebral palsy having need for dental care and an additional anesthetic or cost effectors are involved. But I am not quite clear about what incentives you are specifically referring to, and you indicate that you will address this later in the testimony, and you haven't been able to find out?

Ms. AKERLEY. I am sorry.

Mr. MAGUIRE. Could you help me out just exactly what it is you are saying here? It is important. If there is a weakness in the Maguire bill at this point, I want to understand exactly what it is, what we should do about it.

Ms. AKERLEY. The lack of clarity may also be partly due to the lack of clarity in the administration bill. Reading what we thought we understood was that there would be a system of incentives for providers who provided an integrated type of care so that the poor kid didn't have to go here for screening and here for—

Mr. MAGUIRE. Continuing care?

Ms. AKERLEY. Yes sir, continuing care provider. We think that kind of provision of care should be encouraged, particularly because when you are dealing with low-income children, one of the barriers to their care, and I think we talked about this a little bit at the child health oversight hearing, is there suspicion of the establishment, that medical home that we heard about at that hearing, if they have something analogous to that and the provider who is willing to do it gets the additional reimbursement that is going to be involved in just recordkeeping, then I think that is a worthy sort of provision to put in this kind of bill and I would like to ask Mrs. Hamilton to repeat what she told me while we were waiting to testify about recordkeeping.

Mrs. HAMILTON. Well, as Dr. Carter referred to my brothers, I have several doctors in my family, they would prefer to treat without any cost than to keep the records that are required by medicaid or medicare, which they have done for 25 years. And I was just sitting here thinking, you know, how great it would be if we could get the dental and medical associations to work up something whereby they might be able not to have all of this recordkeeping that is necessary. You have to hire a lot of clerical help just to keep the records of medicaid and medicare patients, particularly in medicaid, and they just prefer and they have done it for years.

Mr. MAGUIRE. Well, I am still not quite sure what mechanism it is that is going to provide, as I would like it to provide, for whatever the additional care and cost is that is involved here where you have special problems as a result of developmental disability.

Are you saying the Maguire and Carter bills are lacking in some respect on that point relative to the administration's bill?

Ms. AKERLEY. I think the administration bill does take that one additional step. It may not be clear, and I have discussed this with some people on how they are going to provide those extra incentives. That does need to be spelled out.

It is important to recognize that if it is going to be a successful program. Some kids cost more to treat and some incentives should be given for providing that more expensive type of care and in a continuing care setting.

Mr. MAGUIRE. Well, we are going to have to consult a little further about this because I am not sure that the portion of the administration bill that you are citing really sets up a difference between the bills with respect to what would be covered.

What they do is, they carve out with respect to followup and case management and so on the concept which they call continuing care and give them extra reimbursement for that.

Under my bill, as I understand it, we do that for everybody. It is not that I disagree with the care concept or encouraging it as much as possible. I am hopeful that we can have that kind of concept apply to all the children in this situation.

Let's talk with you further and try to define what the problem may be because I want to be sure to eliminate it if it is there.

Now there is a difference between the bills in that my bill, and Dr. Carter's bill, mandates services for assessed children, whereas

the administration mandates services for all medicaid children regardless of whether or not they have been assessed.

I thought perhaps that is what you were referring to. The trade offs you get into there are that the administration is more restrictive about what must be provided and in fact allows the States to figure out what they will and will not actually provide in some of these areas, including dental and mental health, whereas the Carter and Maguire bills are more extensive in services that must be provided, albeit they are provided only for assessed children.

If you had to come down on one side or the other, what would you do?

Ms. AKERLY. That is sort of like asking King Solomon to decide who the baby belonged to. You will remember, he recommended cutting it in half.

I think for me to make a choice here when the three of us are representing a group of people would be probably presumptuous and that is called dodging the question because our testimony doesn't, of course, support any one bill but rather the desirable provisions that have come out of the three bills.

What we have asked for is the Moon. You know we want all the good things in your bill, Mr. Maguire, and the good things from Dr. Carter's and those rare jewels in the administration's CHAP bill.

Mr. MAGUIRE. That is a fine answer. I hope you will work with us to figure out which portions of each bill are the jewels.

I want to commend you for putting together this very formidable coalition. That is exactly what we have needed to force the pace. We have had our own problems as, frankly, I think HEW has had, OMB, the dragons that sit over there astride the budget.

If we are going to have a decent program that is going to be cost effective over time, we are going to have to make sure that we do get the coverage, that we don't allow dental or developmental disabilities or mental health to be set aside because somebody thinks we cannot afford to do that. I think that is the most penny-wise and pound-foolish type of strategy that I can imagine.

I thank you for your efforts and advice. I hope that we can continue to consult with each other about pluses and minuses in each bill, so we end up with what is best.

Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Mr. Maguire.

Ms. Mikulski?

Ms. MIKULSKI. Thank you, Mr. Chairman.

I would like to join with my colleague, Mr. Maguire, in amplifying his sentiments about the coalition. Played off in our zeal to serve a particular health problem, we have become, very often public interest groups are as fragmented as the services that are delivered.

I also know the limited resources, particularly financial, that public interest groups such as yours have, and I am glad to see you have been able to maximize yourself not only for power but also to use your mailing lists—one I think Mr. Maguire and Mr. Waxman and I would like to have, by the way.

One of the things the poor kids and rich kids have in common is that if they are a multiproblem child, though rich kids might have a better chance, neither will get comprehensive health care. It has

been my observation that, as you have indicated in your testimony on page 6, the type of services an epileptic child needs who might have other medical problems, the services are fragmented with incredible turf warfares and jealousies; and there seems to be often a hostility, if not a reservation, to cross-disciplinary referral.

That is specifically true I have found, when a medical doctor is treating a child, there seems to be a reluctance very often to refer to mental health services.

Now my question is: Is that your observation that services are really fragmented, and it takes a tremendous amount of that parent's ability to be able to coordinate all the things a kid needs, and that there seems to be a problem with cross-disciplinary referral?

I wonder if there is anything we can put into this legislation, either through reimbursement incentives or any other mechanisms, that you think would maximize coordination in terms of discipline, particularly where they are given an institutional setting, and by institution I mean the big medical institutions, and also how we could encourage cross-disciplinary referrals?

Mrs. HAMILTON. May I respond to the first part of the question?

Ms. MIKULSKI. Surely.

Mrs. HAMILTON. I don't think it is a matter of hesitancy on the part of physicians. I think it is a matter of lack of knowledge of what is available. I think this is certainly true of family physicians. They simply cannot keep up and there are not enough facilities and services available.

I think we could do something perhaps to keep physicians informed of the services available for DD children.

Ms. AKERLEY. I would like to ask if we could have an opportunity to prepare a written response to your question. Again, I am here on behalf of a coalition and I would like to pick their brains and try to give you a helpful response to that.

Ms. MIKULSKI. You see, I am talking about that boy or girl who is going to come into what I would call a major medical institution. In my community it might be the University of Maryland complex. It might be the Hopkins complex, that is a great model because they have the affiliation with the Kennedy Institute and the very relationship that I want does exist.

I don't know how to institutionalize that on a broad base.

Ms. AKERLEY. That is why I would like a little time for the coalition to prepare an answer for you.

Ms. MIKULSKI. Would you?

Ms. AKERLEY. Sure.

In response to your first question, I would say as a parent of a developmentally disabled child, yes. A lot of what you get is luck, talking to the right person at the right time.

Ms. MIKULSKI. You mean talking to the right person?

Ms. AKERLEY. Yes, another mother or perhaps a daddy.

Ms. MIKULSKI. Pardon me. That was a culturally biased remark.

Mr. WAXMAN. We will hold the record open to receive any information you would like to make available to us.

[The information requested was not available to the subcommittee at the time of printing.]

Mr. WAXMAN. Dr. Carter, do you have another point?

Mr. CARTER. Some say we should withhold passage of CHAP until we have a reformed title V program. Do you agree with this, and if so, why or why not?

Ms. AKERLEY. I don't understand the rationale. I don't know who the people are that are asking that question. But for what reason could you justify making a child wait for health care? Because you are going to make a program that hasn't worked better at some indefinite future date? No.

Mr. CARTER. I agree with that. Why do you think HEW will administer a new CHAP program more effectively than the current EPSDT program? Do you think they will?

Ms. AKERLEY. Well, if the bill is carefully drafted, there wouldn't be so many loopholes. We can look to that and say we learned something from the EPSDT program and we are trying to correct it legislatively. I am an optimist.

Mr. CARTER. Of 11 million children now eligible, EPSDT is now taking care of only 2 million; is that correct?

Ms. AKERLEY. More than that for screening, but 2 million for anything beyond that.

Mr. CARTER. Thank you very much.

Mr. WAXMAN. Thank you very much. We appreciated hearing from you.

I would like to now call a panel of Dr. Lawrence Stone from the American Psychiatric Association, and Dr. Bruce A. Copeland of the American Psychological Association.

We would like to welcome you both.

Dr. Stone, we would like to hear from you. We have your testimony which will be a part of the record. If you would, we would like you to summarize it.

STATEMENTS OF LAWRENCE STONE, M.D., ON BEHALF OF AMERICAN PSYCHIATRIC ASSOCIATION (APA), AMERICAN ACADEMY OF CHILD PSYCHIATRY (AAPC), AND AMERICAN ASSOCIATION OF PSYCHIATRIC SERVICES FOR CHILDREN (AAPSC); AND BRUCE A. COPELAND, PH. D., ON BEHALF OF AMERICAN PSYCHOLOGICAL ASSOCIATION, AND ASSOCIATION FOR THE ADVANCEMENT OF PSYCHOLOGY

Dr. STONE. My name is Lawrence Stone, M.D. I am a child psychiatrist from San Antonio, Tex. and clinical associate professor of psychiatry at the University of Texas Health Science Center.

I have had the honor of serving on the White House Conference on Children. I also served as chairman of the Accreditation Council for Psychiatric Facilities of the Joint Commission on Accreditation of Hospitals, and chaired the committee that wrote the standards for psychiatric facilities serving children and adolescents. Further, I am an editor of the "Basic Handbook of Child Psychiatry."

I am here to present the joint testimony of the American Psychiatric Association (APA), the American Academy of Child Psychiatry (AAPC), and the American Association of Psychiatric Services for Children (AAPSC) on the proposed child health assurance program.

Also, you may be interested to know that each of these organizations participates in an informal CHAP coalition composed of more than 20 national organizations representing consumers and provid-

ers of services to the mentally ill and developmentally disabled children of this Nation.

Each organization in this coalition, some of whom you will hear or have heard from during this hearing, shares the precise concern I will address this morning, namely, the need to eliminate any discriminatory legislative limitations placed upon meeting the treatment needs of children screened and diagnosed as mentally ill or developmentally disabled under CHAP.

My testimony will address itself not only to the needs of the mentally ill child, but also to specific concerns with certain provisions contained in the various versions of the pending CHAP legislation.

As you know, each of the child health assurance bills before this subcommittee is intended to replace the early and periodic screening, diagnosis and treatment (EPSDT) program—part of medicaid for over a decade—which was intended to provide low-income children with quality diagnostic and treatment services for identified health and mental health problems. The program today, by the administration's own estimates, reaches only 30 percent of those currently eligible children. Moreover, 22 percent of those screened and found to be in need of treatment do not receive the kinds of services required to ameliorate the physical or mental problems identified.

It has been widely recognized that the EPSDT program has not been working, that data are not available with regard to the scope, quality and extent of treatment provided, and that programs vary in quality from State to State based upon what is in the State plan.

Such unfortunate problems with EPSDT have been particularly significant for the mentally ill child. There are approximately 64 million children under the age of 18 in the United States.

The President's Commission on Mental Health has noted that as many as 9.6 million of these children suffer from mental, nervous or emotional disorders. Yet we estimate that only about 10 percent of this population—900,000 children—are receiving mental health treatment through existing programs.

Gaps in medicaid—for example, flagrantly inadequate reimbursement for psychiatric treatment service—funding cutbacks for the development and operation of community mental health centers, and other similar difficulties contribute to the failure to care for the mental health needs of our children.

CHAP offers Congress the potential to develop and provide a system of active health and mental health care for children in need, children who are being seriously neglected. It can respond specifically to the report of the President's Commission on Mental Health which stated:

What we need is a more comprehensive and coordinated public and private strategy for financing mental health care services where payment is based upon the need for care, not diagnosis.

A CHAP bill could, and indeed would, make such a system possible by not arbitrarily limiting services for children diagnosed as mentally ill.

We are pleased that each of the bills before this subcommittee: H.R. 2159, introduced by this subcommittee's ranking minority Member, Congressman Tim Lee Carter; H.R. 2461, authored by

Congressman Andrew Maguire; and H.R. 4053, introduced by you, Mr. Chairman, on behalf of the administration, takes important steps toward ameliorating the problems which, to date, have plagued the EPSDT program.

Each is a profound improvement upon the proposal submitted by the administration last year, which, for all intents and purposes, said that children may be screened and diagnosed—labeled—as mentally ill, but that they do not have to be treated, once so diagnosed.

We were gratified that the administration, this year, has responded to our concerns and has now eliminated the categorical limitation against treatment of the mentally ill child. Yet problems with some of the current pieces of legislation still exist. Unfortunately, H.R. 2159 and H.R. 4053 do not meet the full range of needs of the child diagnosed as mentally ill under the child health assurance program.

We are most gratified that, in essence, there is not limitation on psychiatric care provided by physicians—that is, psychiatrists and child psychiatrists—in private practice, or in outpatient and inpatient units of general hospitals.

However, we stress that access to the full range of psychiatric treatment settings must be available. Community mental health centers, or other centers meeting standards established by the Secretary in regulation, should not have been singled out for limitations under the administration's proposal and children's residential treatment centers and other inpatient psychiatric facilities should not have been excluded as providers.

Yet, H.R. 2159 and H.R. 4053 currently channel children into only limited types of psychiatric care and restrict access to other modalities which, depending upon the age and individual needs of a child, may be more effective and appropriate.

Regarding CMHC's, I understand that the intent of the administration's legislation is to establish a Federal floor for the amount, duration, and scope of services provided in such settings, thereby assuring a standard for all States, in itself a commendable goal.

However, floors often become ceilings and for CHAP to identify a child's health needs but to limit the availability of care by amount, duration and scope is inconsistent with the goals of the program.

As an example of the effect such limitations will have upon children, we need only look to the kinds of treatment needed for a 4-year-old psychotic child. Such a child may go back and forth between periods of violent outburst and severe withdrawal. His psychosis may take the form of head banging, incessant crying, or noncommunication. He may stay awake all night, lose control over his bowel movements, stop eating, or eat only one thing.

To effectively treat this child, a clinician must not only work directly with the child but also must spend much time working with the parents and consulting with other people significant to the child's health.

If legislation will limit the amount of time the clinician can spend in total care of the child, the duration of the treatment process, and the scope of the services provided, it is the child who, in the end, will suffer.

One of the most important departures EPSDT took from Medicaid was in its mandate to override State plan requirements in some treatment areas by calling for coverage of necessary treatment. If CHAP is to effectively improve upon this concept, it should authorize all needed care without limitation on amount, duration, and scope. Therefore, we would recommend that the committee reported bill adopt the Maguire or Carter provisions regarding ambulatory mental health care.

We are also concerned that at present H.R. 2159 and H.R. 4053 authorize only psychiatric services provided in general hospitals and do not include treatment in psychiatric facilities for severely ill children suffering from mental, nervous, or emotional disorders. This is a serious inpatient psychiatric services flaw.

We urge the committee-reported bill to include psychiatric care provided in child psychiatric facilities where we are assured of the existence of the child psychiatric standards and safeguards established by the Joint Commission on Accreditation of Hospitals. A copy is attached and we ask it be made part of the hearing record.¹ Care provided in child psychiatric facilities assures the facility is subject to the JCAH child psychiatric standards, and includes the development of a treatment plan which appropriately addresses each child's needs.

Thus, we urge the committee to adopt the Maguire bill provisions which would make available under CHAP necessary inpatient care in qualified psychiatric facilities important facilities for meeting the needs of mentally ill children.

In previous testimony before this committee, we have noted that treatment for the mentally ill child is cost effective, that the short-term costs of the full range of services to the child diagnosed as mentally ill has long and short-term benefits.

For example, it has been demonstrated that treatment for mental illness can actually reduce other physical health care costs by as much as 50 percent. A study conducted by Blue Cross of Western Pennsylvania shows that even when the cost of additional treatment for mental illness was factored in, the overall cost to the insurer for all health care was reduced by 31 percent when mental illness treatment was reimbursed.

Moreover, a one-county longitudinal study—1973-77—in Texas demonstrated that mental health coverage reduced hospital stays by as much as 50 percent. Further, in a 1978 study, it was found that among children specifically, the presence of reimbursable mental health care reduced the mean number of physician visits for other purposes by 36 percent.

Indeed, a matched control group, for whom such mental health services were not made available, suffered an increase of 30 percent in the mean number of physician visits during the same period. Thus, each study indicates that appropriate treatment for mental illness actually provides a cost savings for other medical care services.

Diagnosis and treatment of mental, developmental, and emotional illnesses among children are the first line of prevention—one of the stated purposes of CHAP. We wish this subcommittee to under-

¹ The material referred to by Dr. Stone, "Psychiatric Facilities Serving Children and Adolescents," may be found in the subcommittee files. The 4-page preface may be found at p. 227.

stand an important consequence of delayed treatment. A child suffering from a mental disorder will have concomitant developmental problems. If his disorder goes untreated, the developmental lag will be significant enough to become a problem in and of itself.

In treating a 4-year-old psychotic child, a practitioner must deal not only with the psychosis, but also with the consequences of a significant period of time when development has been stopped, regressed, or retarded. The subcommittee should further realize that, to a 4-year-old, even 6 months is a significant period of time—it is one-eighth of a child's lifetime.

Experience indicates that failure to provide a full range of treatment opportunities has already had severe consequences and will continue to have a damaging effect in future years.

However, if a child's mental or emotional illness is attended to as near as possible to its inception, the result will be more normal development through childhood and a far better chance for later entry into society as a productive adult.

The early treatment of emotional disorders benefits not only the individual and his or her family, but also society as a whole. The cost of treatment at an early age is far less than the cost of lifelong disability, social services, unemployment or involvement in the criminal justice system.

Therefore, we urge the committee to adopt the provisions of the Maguire bill and assure children diagnosed as mentally ill under CHAP full access to needed services under that program.

As the subcommittee seeks to develop the most equitable CHAP bill to meet the needs of our Nation's children, I would like to share with you the following further specific concerns:

First, we urge the committee to strengthen incentives to States and to providers of health and mental health treatment to participate in the child health assurance program at all levels—including outreach and followup. Without restructuring of the present medicare reimbursement system, providers will have few incentives to become providers of CHAP services.

Further, sanctions without concomitant, meaningful incentives to States will provide few resources to enable States to improve their program to include the new services envisioned under CHAP, and will ultimately harm the very children the program is designed to help.

Second, we are particularly concerned with the designation of schools or school systems as providers. For the purposes of outreach, schools are excellent. They are frequented by both children and their parents and provide a familiar, nonthreatening setting at which CHAP services could be delivered.

However, we must balance the need for accessibility of services with the greater need to appropriately deliver comprehensive quality medical care. The question is not only whether schools should be the loci of care, but whether medical services should be administered by educators.

We need only look to the experience of Public Law 94-142, the Education for All Handicapped Children Act, to see the problems which may arise without adequate safeguards to assure appropriate medical screening, diagnosis and treatment.

As you know, Public Law 94-142 mandates that all handicapped children must be provided with a free, appropriate education in the "least restrictive"—that is, most appropriate—setting. Children in need of supportive medical services are to be treated or referred for treatment. Yet this has not been the case. Many school systems are refusing to refer a child diagnosed as mentally ill for the mental health treatment which he or she needs for fear that the schools will be required to pay the bill for such services.

Alternatively, they attempt to provide care on site with existing personnel, often not appropriately trained in medical care. Thus, handicapped children are not being served in the manner intended by the Act.

Children cared for through the CHAP legislation must not suffer from the same neglect. If schools are to be deemed eligible providers, then we recommend the legislation be amended to provide that medical services delivered in such settings must be administered by qualified health and mental health professionals, or that contractual arrangements between schools and qualified health and mental health providers be made and honored.

Safeguards must also be provided to assure that any child receiving mental health services in a school, through CHAP, will not be stigmatized because of his emotional illness. The fact that he or she needs and/or is receiving such services must be kept confidential as must all records of the health or mental health services with which the child is provided. This brings me to our next concern.

Third, provisions to protect the confidentiality of children receiving services through the child health assurance program must be included in the legislation approved by the committee. We submit for your consideration in this regard a copy of the APA/AACP model bill on confidentiality of medical records and ask that it be made part of the hearing record.¹

Fourth, another problem which we in the mental health profession have faced is the lack of data available through the EPSDT program regarding the cost and utilization of mental health treatment for children. We find it deplorable that a Federal program has been subject to such poor recordkeeping.

In order that CHAP not suffer from the same mismanagement, we urge that the committee-reported bill mandate the Secretary to require through regulations that States and individual providers report specific types of data on a regular basis. We would think this data, without patient identifier, should include the type assessments, the primary diagnosis and the types of treatment provided, the length of treatment, and the cost of treatment. Such information is vitally needed to measure the effectiveness of the program and the quality of the care provided to our children in need.

This committee has taken major steps in the past to improve upon the administration's CHAP proposal. We urge you to again take the critical leadership role in assuring that the child health assurance program which will be approved by Congress this year, this International Year of the Child, will meet the full range of health needs of our children who are most at risk.

¹ The articles referred to Model Law on Confidentiality of Health and Social Service Records and The APA Model Law on Confidentiality, excerpts of American Journal of Psychiatry 136:1, January 1979 may be found in the subcommittee files.

Mr. Chairman, I appreciate the opportunity to have presented this testimony before your subcommittee. I would be pleased to respond to any questions you may have. I further hope you and your staff will continue to work with the organizations I represent today to seek ways of meeting all the needs of our Nation's mentally ill, both young and old alike.

[The preface to, "Psychiatric Facilities Serving Children and Adolescents" follows:]

PREFACE

Until now, no nationally developed and applied set of standards has existed in the field of psychiatric facilities for children and adolescents. Nevertheless, children's and adolescents' psychiatric facilities of quality currently do exist and function well with a wide range of patterns of organization and delivery of services. Standards for ensuring high quality of psychiatric facilities and services should not be based on rigid, monolithic rules and regulations, nor should the overall functioning of the facilities and the methods of delivery of services reflect such institutionalized characteristics. Therefore, nationally applicable standards for such facilities must be sufficiently flexible to ensure their relevance to the realities of the field yet specific enough to ensure the high quality of services and effectiveness of organization within these facilities.

The standards in the *Accreditation Manual for Psychiatric Facilities Serving Children and Adolescents* were developed with a recognition of two important and perpetual processes, i.e., *humanization*, as represented primarily by the realities of the child or adolescent patient being served by the facility, and *institutionalization*, those things necessary to carry out effectively the goals and objectives of the facility. Significant consideration was given to each of these processes and to the all-important integration of the two. The two processes were conceptualized as follows:

HUMANIZATION

INSTITUTIONALIZATION



If the process of *institutionalization* alone were considered, inevitably the procedures, roles, and power would serve only the institution; the *humanization* process would be left out and the needs of the people would not be served. Conversely, if only the *humanization* process were considered, without regard for roles and procedures, inconsistencies and instability would develop, and chaos and failure would eventually result.

In the integration of the two processes, however, the *humanization* process inevitably tends to go unilaterally toward the *institutionalization* process. Therefore, the facility's direction of attention should be in a cycle, always starting from and returning to the process of *humanization*. The goals of the facility are based on the needs of those being served, the "people" part of the *humanization* process. Roles, developed from the goals, define who in the organizational structure is to do what, and who has power. In order to achieve the goals of the facility and to ensure understanding and maintain control of

services being offered, policies are established; in order to carry out the policies routinely and consistently, procedures are established.

In the development of these standards, primary consideration was given to the achievement of a balance and integration of both processes within all psychiatric facilities serving children and adolescents. Every facility should periodically review its *humanization* and *institutionalization* processes; it should reexamine the needs of the population served, and, in light of these needs, reappraise the appropriateness and effectiveness of its goals, services, programs, roles, policies, and procedures. The *humanization* and *institutionalization* processes should focus first on the individual child or adolescent, then on the family and significant others, including schools and other involved institutions in the community, and then on the overall environment and social processes that impact upon the child or adolescent.

In addition to consideration of the two basic processes described above, sets of fundamentals based on certain priority considerations and essential elements of facility organization and delivery of services were developed. The standards focus on each and emphasize their integration and correlation.

Fundamentals of Care:

The nature and intensity of services that are to be provided to the child or adolescent patient, which depend on the level of responsibility that the facility assumes for the care of the child, i.e., the penetration-of-care concept.

Fundamentals of the Facility:

The clinical and administrative aspects common to all facilities.

Fundamental Needs of the Patient:

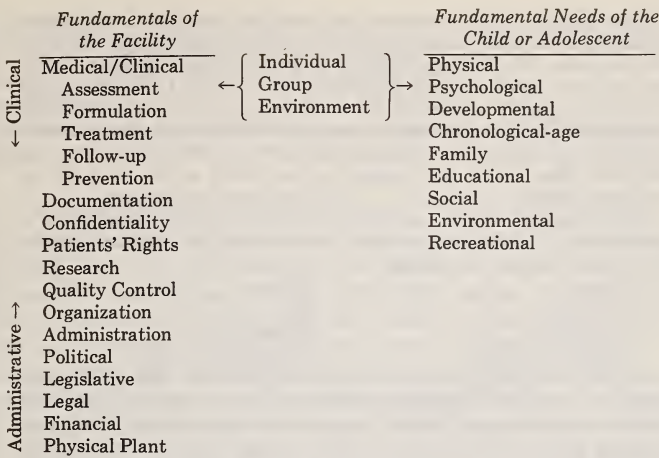
The needs of the child or adolescent.

Fundamentals of Service:

The psychiatric clinical services of assessment, formulation, treatment, follow-up, and prevention..

Since there are institutional aspects common to all facilities, such as governing bodies, staff organization, rules, and regulations, a section of standards for all facilities was developed. A penetration-of-care concept was also formulated, which takes into account the level of responsibility a facility assumes for the life of the child or adolescent patient; this level of responsibility is the determining factor in the nature of the standards to be applied. Accordingly, separate sections of standards were developed for inpatient, partial-day, and outpatient facilities and services.

Potential administrative and clinical conflicts, or the resolution of the question of who should do what, were important in the determination that the standards be function-oriented. The relationship of facility functions to patient needs was outlined as follows:



The *medical* or *clinical* services carried out by the facility include the *assessment* or examination, the *formulation* or determination of what is wrong, the *treatment* or therapeutic programs, *follow-up*, and *prevention*. There are other professional or clinical aspects that must be considered in the operation of the facility: there must be *documentation*; *confidentiality* must be assured; and *patients' rights* must be protected. *Research*, *quality control*, and *organizational* aspects fall in the center of the spectrum of services, as these have both clinical and administrative components. At the administrative end are *political*, *legislative*, *legal*, and *financial* considerations and the operation of the *physical plant* itself. In all of these, there must be consideration of the *individual* patient; the *group*, family, peers, significant others; and the *environment*, including the social systems, schools, local government, and other facilities.

There are some individuals who are qualified to assume responsibility for all of these functions or services. Others work in partnership or with a group of other qualified individuals to ensure that all of these functions are carried out in an efficient and effective manner. The determination to organize the standards in a function-oriented manner signifies recognition of the fact that there is a flexible range in which a psychiatric facility serving children and adolescents can be managed, personnel utilized, and services delivered.

As part of the *humanization* process, the fundamental needs of each individual child or adolescent patient must be delineated. Each facility is responsible for assessing, in some depth, each of the fundamental needs: *physical*; *psychological*; *developmental*; *chronological-age*; *family*, which includes ethnic and cultural characteristics and backgrounds; *educational*; *social*; *environmental*, which includes socioeconomic factors; and *recreational*.

The requirements for patient assessment depend upon the level of penetration of care the facility offers. An inpatient program assumes heavier responsibilities than partial-day or outpatient programs for the child or adolescent's normative growth and development and child rearing, as well as therapeutic responsibilities, and, therefore, must give considerably more

depth and detail to the assessment. All facilities must take into account children's and adolescents' normal developmental needs and growth potentials, as well as the pathological aspects of their individual disorders. Treatment and care requirements, therefore, also vary according to the penetration of care of the child or adolescent. While all facilities are not responsible for providing treatment or programs to meet each of the fundamental needs, each facility is responsible for assessing these needs and for ensuring that they are being met either within the programs of the facility or by the family or significant others.

For the purposes of these standards, the criteria for the determination of qualifications of individuals providing services were conceptualized on the basis of the following parameters:

Training	Science
Supervision	Art
Consultation	Philosophy
Practice/Experience	Tradition/Mystique

Providers of services may start with *training*, then work under appropriate *supervision*. As their knowledge increases and their need for supervision lessens, *consultation* may become the primary learning modality; they then move into *practice* with *experience*. Providers of services may also start from the other direction, i.e., begin with *experience*, either job-related or from their personal lives, and then acquire specific *training*. How far up the training ladder such individuals must go will vary. For the provision of certain services, *training* and demonstrated competence are necessary; for others *experience* and demonstrated competence are sufficient; and in some cases either *training* or *experience* combined with demonstrated competence is appropriate.

Qualifications of individuals in relation to specific functions are also related to the reality that services are based on *science*, *art*, *philosophy*, *tradition*, or some combination of these. Some services have a more definitive *scientific* basis, while others are based largely on an *art* of performance. Some services evolve from a *philosophy* or a particular kind of approach, and others originate primarily from a *tradition* or a *mystique*.

Within the standards the *scientific*, *art*, *philosophical*, and *traditional* aspects of psychiatric services to children and adolescents have been correlated with the *training-supervision-consultation-practice* ladder. In so doing, certain specific qualifications have been set forth for the performance of certain functions and provision of services, while other qualifications have been purposely stated in broad terms.

The *Accreditation Manual for Psychiatric Facilities Serving Children and Adolescents*, in accordance with all of the important considerations presented above, attempts to provide standards for meaningfully specific and appropriately flexible patterns for the optimal organization of the facility, the most effective utilization of personnel, and the delivery of patient services of quality. Finally in keeping with the recognition of the dynamic principles of the *humanization* and *institutionalization* processes, not only should all facilities periodically reevaluate their, goals, services, programs, roles, policies, and procedures, but these standards, too, must be periodically reevaluated and revised as indicated by future experiences and by the changing of the criteria for the delivery of psychiatric services of quality to children and adolescents.

Lawrence A. Stone, M.D.

Mr. WAXMAN. Thank you very much for your testimony.

We will, without objection, receive the report of the American Psychiatric Association on Confidentiality.

Thank you.

Let's hear from Dr. Copeland and then we will have questions for you both.

STATEMENT OF BRUCE A. COPELAND, PH. D.

Dr. COPELAND. Mr. Chairman and members of the subcommittee, thank you for the opportunity to testify today on the proposed Child Health Assurance Act of 1980. My name is Bruce Copeland, and I am here on behalf of the American Psychological Association and the Association for the Advancement of Psychology.

I am an assistant professor of psychiatry and behavioral science, and child health and development, at the Children's Hospital National Medical Center and George Washington University Medical School. Previously, I served as a clinical director of a large residential treatment center for children and adolescents in Massachusetts. In addition, I have served as the director of the adolescent treatment program at Connecticut Valley Hospital.

Consequently, I feel I have had the experience to comment about the provision of mental health services under CHAP.

The two associations I represent today have as their constituency over 50,000 psychologists, many of whom specialize in developmental psychology and clinical child psychology. Among psychologists' many roles, two are of primary importance. One is as a diagnostician, both in the development and use of assessment techniques to identify mental, emotional and learning disorders. The other is as a health care provider who develops and delivers high quality therapeutic programs for optimal growth and development of the child.

We are participants in the ad hoc coalition for CHAP and endorse their testimony as well.

We have testified on previous legislation to improve the early and periodic screening, diagnosis and testing—EPSDT—program, and we have seen this legislation wend its way to the House floor, only to be lost in the hectic, final days of the 95th Congress.

The need for CHAP has not diminished. If anything, it is increasing as more and more lower income families are priced out of basic health care services by the inflated cost of living in this country.

The intent of the bills before the subcommittee is clear, to provide access to quality health care services for needy children and to emphasize the important role played by preventive health care in childhood. Indeed, child health care is preventive in nature because sound physical and mental development must be assured for a healthier adult life. The physical aspect of human development is taken care of by each of these three bills.

We wholeheartedly support this. But it is only one side of the coin. Services must also be assured for the mental and emotional development of these children.

H.R. 4053 simply is not a sufficiently comprehensive bill. We feel that the Maguire-Waxman bill and the Carter bill are both preferable to the administration's proposal.

H.R. 4053 requires that States provide ambulatory mental health services through community mental health centers or other recog-

nized providers of care. But the State can limit the amount, duration and scope of these services and there is no guarantee that the HEW Secretary's minimum on mental health services would be adequate. The benefits to be gained from a requirement for mandatory and unlimited ambulatory mental health benefits, as contained in H.R. 2159 and H.R. 2461, we feel would far outweigh the costs involved.

Ambulatory mental health services must be made available, along with medical check ups and inoculations, for a number of reasons.

By considering the potential exclusion of mental health benefits, the Government has opened the door to many mental health problems that could be cured by early identification and treatment.

As an aside, I think you will find that kids who are not screened and treated early are likely to end up in one of two institutional settings; that is, either in the correctional system, the juvenile justice system, or State facilities for the mentally ill.

I think we have to take a look at what the impact of sitting around and waiting and then trying to treat these children when they reach the age of 15, 16, or 17.

I would ask you to consider a couple of observations: One is that the cost of providing those inpatient services when a child reaches adolescence is extremely expensive. That cost is really associated with very limited therapeutic services as well. Estimates that I have heard suggest that even maintaining a child in the State hospital system for 1 year is approximately \$30,000 a year or more.

So by not providing services, we are paying an excessive amount for later health care for potentially limited benefits.

I think we have to keep a long-range perspective in terms of what this current CHAP proposal can accomplish for us.

Now, the potential imbalance between the provision of mental health services is especially difficult to justify in light of recent congressional concern over developmental health.

I would call your attention to Public Law 95-602 which amends the Rehabilitation Act of 1973, Congress defines a developmental disability as a condition which (a) is attributable to a mental or physical impairment or combination of mental and physical impairments; (b) is manifested before the person attains age 22; (c) is likely to continue indefinitely; (d) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and (e) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated.

This definition specifically addresses children and adolescents, as does CHAP. The law also calls for treatment, not just identification, of physical and mental developmental problems.

But the Developmental Disabilities Act is limited to providing for individuals with severe functional deficits that are long term. The proposals before this committee today, by providing early diagnosis and treatment, would reduce the population which is ultimately

served by Public Law 95-602 and could serve to substantially mitigate the severity of the conditions of a large number of those cases which otherwise develop into Public Law 95-602 beneficiaries.

Excluding therapeutic services would have a deleterious effect on the child who is diagnosed under CHAP as having a mental or emotional problem, but who then cannot get treatment because it is not available under the same program. Diagnosis without treatment is irresponsible health care. In addition, the label of emotional or mental impairment can mean a lifetime of discrimination and social stigma for people who already exist under a handicap. As noted 2 weeks ago during the hearings on the Mental Health Systems Act, one of the main problems facing mentally and emotionally disturbed people is stigma and public misunderstanding.

A major problem with the EPSDT program is that it does not mandate followup treatment. By not including ambulatory health care services, CHAP would similarly contribute to the stigmatization of children, by labeling them as having a mental, emotional or learning disorder—but not helping them with that disorder.

If doubt remains that disadvantaged children are in need of ambulatory mental health services, let me refer to a 1977 report by the Children's Defense Fund on the EPSDT program. This report documents the fact that developmental problems are among the most common childhood afflictions, particularly in poor, high risk and disadvantaged children. It states that:

The combined group of mentally retarded, seizure disorders, neuromotor disabilities, school learning problems and emotional disturbances, comprises over 17 percent of all children, a percentage that is higher than most other conditions such as anemia or tuberculosis.

The CDF report also contains data from another recent study which states that:

The most prominent of the child health problems that have emerged in the past decade or two are the behavioral and schooling problems found in children of all ages. Between 20 and 30 percent of children entering first grade have been identified as having behavioral and emotional problems * * *. The prevalence of preschool behavioral problems in various populations varies from 8 to 50 percent * * *; and 10 to 30 percent of school children experience significant problems or behavioral difficulties.

I can interject from my own experience at Children's Hospital, we see a tremendous number of inner city children who by the time they reach our inpatient services there is very, very little we can do to deal with multiproblem families and severe difficulties.

The key factor here is that we must impact services early on.

More recently, the President's Commission on Mental Health has also documented the necessity of providing mental health services to children. In recommending developmental assessment and treatment for children, the Commission stated that:

The delivery of a biologically healthy infant does not guarantee that the child's psychological and social development will be smooth. It is vitally important to detect and attempt to correct at the earliest stages the problems of physical, emotional and cognitive development which can lead to emotional maladjustment and learning difficulties.

Ambulatory mental health services are generally effective within 6 to 10 visits. These brief therapeutic interventions have been shown to be remarkably effective in reducing the chance that

emotional disturbance will lead to physical complaints, further behavior problems, and poor school performance.

I did a little research and I was able to document the existence of some 23 research studies which currently demonstrate that the provision of ambulatory mental health care services will significantly reduce the subsequent utilization of medical services. This includes hospitalization. It includes subsequent medical office visits and things like the ordering of various laboratory tests.

The range in these studies suggests that up to 70 percent of subsequent medical usage can be reduced by a very limited application of outpatient psychotherapy. I would briefly cite one study in which two researchers:

Found readily available psychological services significantly reduced the use of medical care.

Further, this reduction was extended for 5 years after the psychotherapy without additional treatment. About 50 percent of the group studied received only one psychotherapy session yet they showed a substantial reduction in medical use of about 60 percent. About 25 percent of the group received two to eight psychotherapy sessions and they reduced their medical care use by 70 percent after 5 years.

The remainder of the group, about 25 percent, stayed in therapy for more than nine visits and they reduced their outpatient medical use by 51 percent and their inpatient medical use by 81 percent.

I think it is being proved all the time that it is a cost-effective program which focuses on the ambulatory and outpatient mental health care services.

The mandated addition of mental health care may significantly reduce the utilization of medical services—especially unnecessary medical tests and hospitalization. This will have a positive effect on the much-needed effort to reduce health care costs, while also providing effective health care services.

I would add that the President's Commission Task Force on Mental Health and American Families includes another important point about services to children: That mental health disabilities—

* * * must be distinguished from biological disorders which give rise to the same signs and symptoms. It is urgent that mental health professionals join the general health care teams not only to recognize the problems but to assist pediatricians, family physicians, and nurses in providing effective help.

In keeping with these recommendations, we ask that the four core mental health providers—psychologists, psychiatrists, clinical social workers, and psychiatric nurses—all be called upon to function within their specialties under this act. This will insure access to a wide range of child mental health specialists. It is very important to broaden the base of available mental health manpower.

I know in the case of psychiatry and psychology we have a limited number of providers who have extensive experience in working with children and we need to broaden that base so that the services are comprehensive and appropriate.

For example, in a letter dated February 24, 1978, Dr. Melvin Sabshin, medical director of the American Psychiatric Association, points out to Dr. Daniel Whiteside, Director of the Bureau of Health Manpower in HEW, that "nationwide there are only 2,500 child psychiatrists, or 1 child psychiatrist for every 30,800 children * * * clearly a severe shortage."

Psychologists are recognized as autonomous health care providers in all 50 States. They are especially skilled in the treatment of

behavioral problems. In addition, psychologists conduct the major portion of all behavioral research, including the study of childhood and adolescence.

More than 3,000 doctoral-level psychologists work in CMHC's as their primary setting. They are administrators as well as service providers and are actively involved in the CMHC network. Numerous other Federal health programs recognize psychologists as autonomous practitioners, including the Federal Employees Health Benefits, CHAMPUS, and the HMO program. Acknowledgment of the important role and contribution of psychologists in the CHAP program would significantly enhance the accessibility of mental health services for our Nation's children.

In summary, I would like to say that CHAP is an important step forward in establishing a system of adequate health care and prevention for underprivileged children. We applaud the initiative shown in providing ambulatory mental health services for this underserved population.

The President's Commission on Mental Health has strongly recommended that any program such as CHAP should have a strong mental health component. By including ambulatory mental health services and, specifically, by recognizing psychologists as autonomous health care providers, you will insure that CHAP will be a comprehensive, high quality health care program, one that will far surpass its predecessors and will serve as a model for future preventive health care activities.

Mr. WAXMAN. Thank you very much for both your testimonies.

Dr. Carter, would you like to lead off the questioning?

Mr. CARTER. Thank you, Mr. Chairman.

Should psychologists and psychiatrists be reimbursed differently? We can hear from each of you.

Dr. STONE. Dr. Carter, I am not exactly sure how you mean the question.

Mr. CARTER. How much simpler can you make it? I laid it right on the table. Should psychologists and psychiatrists be reimbursed differently?

Dr. STONE. Yes.

Mr. CARTER. How and why?

Dr. STONE. I think there is a different service being provided. I think, in many situations there are similar services. Under those circumstances, where there is a difference in service, there should be a difference in reimbursement. I think the nature of the disciplines and the nature of their clinical work at times differs, and because of that there would be a differing reimbursement.

Now if you are referring to the question of should they be reimbursed in quantity or quality——

Mr. CARTER. In both.

Dr. STONE. I think because the services are different; yes. The answer would continue to be "Yes." We should look at it very thoughtfully and carefully.

I think in all of the services we are talking about, a determination should be made as to the most effective means of delivering reimbursement for the appropriate services that are being provided.

Mr. CARTER. Doctor, do you agree?

Dr. COPELAND. No, I don't. My position would be that when the two professions are providing essentially the same services to children, and I see the provision of a majority of psychotherapy services under this bill as being equivalent, I think they should be reimbursed as well as the other health services provider groups, at the same rate.

If they are providing services which are essentially different, I think the reimbursement rates are contingent upon the nature, extent and type of those services. But where they overlap in the provision of services, I think they should be reimbursed at the same rate.

Mr. CARTER. Can you tell me how these two specialties differ in the type of services they offer?

Dr. STONE. I think the services, when they differ, they differ primarily on the basis of the background and training of the two different disciplines.

A psychiatrist has a medical training and a psychologist—I won't try to speak extensively for that, but there is a difference in the level of training.

So whenever we are talking about the difference in service, bringing into bear, particularly in the assessment and continued evaluation of the child, the whole range of experiences and knowledge that one gets from the medical background, the medical training and the medical experience primarily in areas of the biological aspects of the child's development.

Mr. CARTER. Do you have a response to that?

Dr. COPELAND. Yes. There are certain services which psychiatrists do provide which psychologists do not, and that has to do with the application of medications and certain medical treatment such as ECT, et cetera.

My position would be that psychologists are extensively trained in the provision of mental health services both for children and adults. A graduate training program in psychology is generally 4 full years of academic study dealing specifically with mental and emotional problems, including 1 full year of internship within an appropriate clinical setting.

In addition, the majority of States currently also mandate for psychologists to be licensed and certified that they have an additional 2 years of training within an organized health care setting.

So I see the training as very appropriate and adequate.

Mr. CARTER. The administration bill limits the amount, duration and scope of services in community mental health centers. Do you see this as reasonable and how would this best be done?

Dr. STONE. No, I think that there should be a very careful assessment in terms of limitations of the amount and scope of treatment. I think that issue is what has been brought out in testimony all morning. When an attempt is made at specific kinds of limitations, it bypasses sound clinical judgment.

Very often it forces a child, because there is not sufficient financial support for them to continue in a less restrictive treatment program, into a hospital or it excludes them from those kinds of care.

So I think that if there are limitations, I would urge the committee to look at it from the standpoint of limiting it on the basis of

the clinical judgment, the quality control, and the kind of peer review mechanisms that we now have fortunately gotten started.

Mr. CARTER. Do you agree, Doctor?

Dr. COPELAND. Yes. I would add another point here. When you limit services you have to take a look at who you cut out of a system. The types of kids that you cut out of the system are the kids who are most severely disturbed and need the services most. These are the kids who, as I said before, are going to end up in the correctional facilities and the State hospitals and who are going to in the long run receive much more costly care.

So when you arbitrarily limit, you cut out of the system the kids who are most in need of the service. I think that is a point that must be added.

Mr. CARTER. What does your treatment consist of as a psychologist?

Dr. COPELAND. There are a number of treatments that are applied, including outpatient, insight-oriented psychotherapy and other techniques such as biofeedback, family therapy and group therapy, a whole host of them.

Mr. CARTER. How does your treatment differ, Doctor?

Dr. STONE. The treatment may include all of those and it may also include the administration of medications. I think probably one of the basic elements that we have not heard talked about is the importance of the treatment that goes on during an actual assessment.

I think the establishment of a differential diagnosis, which is a term which I think most medical treatment would recognize as far as arriving at a formulation of treatment, is critical. It is a medical assessment, based on all the fundamentals of the child, including the biological, the psychological and the development, the things that we have heard Dr. Carter mention. The result is to be able to impart the recommendations to a family of the child or to the school personnel, or to the child about what that child may need and also what he or she does not need. It is extremely important.

That is one of the distinct characteristics. I could go on in a number of different areas as far as our specific kinds of treatment.

Mr. CARTER. Have you had experience with dyslexic kinds of children?

Dr. STONE. Yes.

Mr. CARTER. What treatment do you order for them?

Dr. STONE. It depends on the nature of the dyslexia and whether it accompanies other kinds of difficulties. I have treated them by working out various programs with the school where preliminary treatment would be carried out within the school system.

We have worked out remedial kind of programs for the family. I also have treated it with medication. I have treated such children in my office in psychotherapy. It has depended more on a constellation of factors than simply on the diagnosis of dyslexia.

Mr. CARTER. What drugs would you use in treatment of dyslexia—you said you used them in treatment of dyslexia—and why? I hardly understand that, using medicines in this case for treatment of dyslexia.

Dr. STONE. That is why I make the point. I would use medications depending upon the constellation of factors and not on the particular diagnosis of dyslexia per se.

There are occasions where I have treated children, with dyslexia, but I am not treating them specifically for that, although some do. I would treat them with imipramine, methylphenidate, or some others.

Mr. CARTER. What do these drugs do for a dyslexic child? As I understand it, the child reads from right to left and down up. They have a mirror image of whatever they see.

Dr. STONE. That is right.

Mr. CARTER. I don't believe you can find a drug that will alter that pattern. Some of the greatest people we have had in the world, including Leonardo DeVinci, were dyslexic.

Dr. STONE. I agree. I would not treat the dyslexic alone that way. It must be a constellation of disorders.

Mr. CARTER. How would you treat it, Doctor?

Dr. COPELAND. I am not an expert in dyslexic children. I will preface my comments with that.

There are two routes. I think what the child needs is excellent remedial or compensatory education programing to deal with dyslexia. That is, if the child is young enough and the disability has not developed extensively, I think there are remedial approaches, special education approaches, that can be used within the school.

If the child is older, then I think you need to teach the child how to compensate for the deficit.

There is one other area for the severely dyslexic child which needs to be looked at. That is, that you frequently find these kids when they get into the school system very early on will fall well behind their academic classmates. This creates a series of emotional problems for the child who is striving to accomplish, may be very competent in other areas, but because of that disorder cannot keep up academically.

That has some profound effects on self-image, and eventually, how they get along with peers. We frequently find that dyslexia, as a consequence, will produce problems in self-image and self-esteem that need to be dealt with therapeutically.

So in some cases, and this is dependent upon assessment, you may need to provide some additional services to the child.

Mr. CARTER. Thank you very kindly.

Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Dr. Carter, for your questions.

Mr. Maguire?

Mr. MAGUIRE. Thank you, Mr. Chairman.

The report of the President's Commission on Mental Health reported that there may be an insufficient number of psychiatrists specifically trained to treat children. Interestingly enough, Dr. Copeland also made the point in his statement, quoting a HEW source as saying, nationwide there are only 2,500 child psychiatrists, one child psychiatrist for every 30,000 children.

The HEW source described this as clearly a severe shortage. Is that figure an accurate one, Dr. Stone, do you know?

Dr. STONE. I don't know precisely, but I would estimate that it sounds fairly accurate. The shortage, as I see it, has generally been

in access and it has been in underutilization. Where we have had specific programs and could generate sufficient funds for early child development programs, we have been able to get together teams which would include child psychiatrists as well as other psychiatrists to provide those services.

One of the big problems has been that we have the teams but in areas where there is not sufficient funding, we end up not having sufficient personnel, regardless of who it is.

I think that is one of the major advancements that CHAP offers.

Mr. MAGUIRE. Dr. Copeland, do you know how many psychologists work predominantly with children? Do you have any figures on that?

Dr. COPELAND. Our best estimates are that there are approximately 3,000 qualified psychologists who work primarily with children and adolescents.

Mr. MAGUIRE. You say in your statement there are 3,000 that work in community mental health offices.

Dr. COPELAND. It is the same number but different providers for the two groups.

Mr. MAGUIRE. So 3,000 or so is not all that more than child psychiatrists?

Dr. COPELAND. That is correct.

Mr. MAGUIRE. Would you say there is a shortage of child psychologists?

Dr. COPELAND. Given the need, I would say there is a shortage across the board in all health service practitioner groups for people who are trained and experienced in working with children.

I think part of this is that the historical development of the recognition of mental health problems in children and the subsequent treatment of those problems is of relatively short duration compared to the equivalent development for diagnosis and treatment of adults.

This is a fairly new developing field. I think that the manpower has not quite caught up with the identified need.

I think the other factor is that we have seen an alarming increase over the last 10 years in the incidence of childhood and adolescent problems. Now there are a lot of theories about why the incidence has increased. But I think most experts would agree that it is a greater problem now than it was even a decade ago and that we have more kids who are in need of services and a lot of societal factors may enter into that pattern.

Mr. MAGUIRE. Is it also related to the fact that when you are dealing with kids you are generally not just collecting a check from one bank account, from one adult who may be seeing you x hours a week, but you get mired down in all the difficulties of reimbursement and paperwork and so on?

Dr. COPELAND. Yes, that is part of it.

Mr. MAGUIRE. There may be a divergence, then, between the need that we have had and the ability of providers, and the willingness of providers, to provide for this type of population.

Dr. COPELAND. There is another kind of subtle factor and that is that the difference between a child seeking services and adults is that adults can come in on their own. Kids are very unlikely to

recognize problems in their own development and to seek out services.

When it comes to dealing with kids, it is a fact that the children manifest the problems and the parents have to identify them and be sufficiently concerned to bring the child in for treatment. That is one difference, they don't generally seek treatment on their own.

Mr. MAGUIRE. Do you have anything to add, Dr. Stone?

Dr. STONE. Yes. I think one of the major problems historically, has been that we approach the child from the standpoint of the individual. However, we must include the family and all significant others. That requires people of broad background as far as training is concerned, but it also requires a number of other people to get involved in the treatment very often.

It requires a very clear direction for treatment, but once treatment is undertaken, it takes followup. It takes involvement with a number of the community areas. Those are the kinds of the things I am not sure that we can arrive at exact formulas for reimbursement.

Certainly one of the major problems that I see and have encountered as far as children are concerned has always been that there is simply a lack of funds for those children who need to be cared for. Where we have identified them, where we have had programs to identify many of the problems, we have not carried such programs far enough in terms of what we might call outreach or followup.

I think both of those are extremely important.

Mr. MAGUIRE. Do either of you have any additional suggestions as to how we might better link up provisions of mental health, general health services, assuming that this has been a problem in the past?

Dr. STONE. I certainly would have many of them come to mind right at the moment but I think I would like to leave the question open, if I may, for the three organizations I represent to submit some written responses because that is an area that many of them are very concerned about.

Mr. MAGUIRE. With particular reference to the legislation.

Dr. STONE. Yes, sir.

Dr. COPELAND. I think we have had a good start by building an equivalence in the bill between mental and physical disorders. We talk about them in separate terms. I don't see them as being separate. There is all kinds of evidence that suggests that there is a substantial interplay.

I have even seen figures quoted, for example, that of individuals who seek services from a general practitioner of a medical nature that estimates are approximately 50 to 80 percent of those patients presenting are presenting primarily with psychologically based problems or medical conditions that have a strong relationship with emotional problems, so I even have difficulty separating them out totally.

Mr. MAGUIRE. It's one thing to say, "Yes, we are going to reimburse," and another thing to have an integrated delivery mechanism with followup and proper referral interrelationships, and so on. Those are the questions that I am concerned about and I know that Ms. Mikulski is concerned about.

Why don't we leave the record open for any additional comments that either of you might have?

Dr. STONE. Could I make one comment on that?

Mr. MAGUIRE. Yes.

Dr. STONE. I have been a general practitioner, family physician, prior to going into psychiatric and child psychiatric training. I must say that I think that many of the problems of reintegrating mental health care of our children with the medical care has been created partly by processes of regulation, and by the way in which we have written for funding mechanisms. Traditionally, certainly when I was in family practice, it was not that big of a problem for me to care for, and was certainly even easier at times for me to care for the needs of children, although I didn't know as much. I could even get involved in treatment teams of people because, then I wasn't mired in as much regulation as we have.

If we can look closely at that, we may be able to bridge some of those gaps.

Mr. MAGUIRE. Thank you.

Mr. Chairman, if we could leave the record open at this point for additional comments on that question.

Thank you.

Mr. WAXMAN. Thank you.

Without objection the record will be held open for any additional comments you wish to submit.

[The information requested was not available to the subcommittee at the time of printing.]

Ms. MIKULSKI. Mr. Maguire raised the issue of manpower shortages. There is a general observation I would like to make.

One of the reasons there is a manpower shortage is that there aren't among young idealistic people, they don't perceive that there are job openings in these particular careers. I went to graduate school on a National Institute of Mental Health grant during the days of the Great Society. I had money to go to school and I thought I was going to have a job at the end of it.

I think both of those things have radically altered; therefore, No. 1, if people want to go to school there aren't the bucks to help them get through it, and, No. 2, they don't know if they have a future, particularly in some of the less autonomous practicing areas, like social work and psychiatric nursing. I think they are victims of a lack of coordinated, clear and consistent Federal policy that says we are going to be doing this not just this year but over a long haul.

Are these kind of your sentiments?

Dr. STONE. Yes; that is very much the point that I was making, I think the funding has in a way dictated where the lack of services have been and also where the people who were trying to get them couldn't.

There has been a great deal of inconsistency, and if we start up something and we do not plan for it down the road, I think that has hurt individuals as well as our delivery system. The patient is the person that I feel most strongly about.

Ms. MIKULSKI. My time is going to be limited. We are going to have to go to a vote.

I appreciate the validation of my point.

I have another question for you.

In your testimony, I want to make this clear, were you also encouraging the reimbursement of other mental health professionals in addition to the psychiatric providers?

Dr. STONE. I would certainly hope so. When we talk about the mechanism, I don't want to try to get into that because I am not an expert.

Ms. MIKULSKI. I know you speak for three major organizations that are primarily medical training based.

Dr. STONE. They are team oriented, two of them are more medical training base. APSC is team oriented.

Ms. MIKULSKI. I understand that they do support the concept of funding of a variety of mental health professions depending on diagnostic patient need, and so on; is that right?

Dr. STONE. Yes.

Ms. MIKULSKI. The only other questions I have with both Dr. Copeland and yourself is to pick up on what Congressman Maguire said and what I raised with the other panel earlier. How do we develop a strategy to maximize cooperation among those fragmented services across disciplinary referrals and even in the area of diagnosis? Dr. Copeland, I was struck by your comment that mental health disabilities must be distinguished from biological disorders which also give rise to the same signs and symptoms.

When I was a residential treatment social worker I often saw the same symptoms in children and yet one would have a neurological problem that needed to be treated and the other would have a very severe psychiatric disease order.

My concern was that where the kid went was due to the bias of whoever was most frequently observing that kid. I happen to be somebody who believes we should also have a physical first before he had them see the psychiatrists. Most of my colleagues at that time in social work, which was in the early 1960's, really had a little thing going with anti-Freud and didn't want to see if the kid had diabetes as well.

It has been outlined, I hope, that you could recommend to us how we can have an integrated system that really does the proper diagnosis and then follows up.

Thank you very much for your testimony. I just wish that I felt that everybody in your fields felt the same way as you did.

Mr. WAXMAN. Thank you.

I want to thank both of you for your testimony and join my colleagues in telling you how much we appreciate it and how helpful it will be to us in evaluating this legislation.

Thank you very much.

We are going to break now and come back at 2 o'clock, at which time we will hear first from the panel on outreach services.

[Whereupon, at 12:10 p.m. the subcommittee recessed, to reconvene at 2 p.m.]

AFTER RECESS

[The subcommittee reconvened at 2 p.m., Hon. Henry A. Waxman, chairman, presiding.]

Mr. WAXMAN. The meeting will come to order. We have on the schedule now a panel on outreach services, Hazel Clarke, health

coordinator, Tri-City Citizens Union for Progress, Newark, N.J., Howard M. Perlman, president, HSC Service, Inc., Denver, Colo., Paulette Pope, chairperson, Baltimore Welfare Rights Organization. We welcome you all.

Mr. MAGUIRE. Could I make a brief comment.

I am pleased to have Hazel Clarke from the State of New Jersey, who is the community health coordinator of the Tri-City Citizens Union for Progress in Newark. Last year we were fortunate to have Rebecca Andrade, who was director of the program, appear before us to describe the very innovative and effective work that they have done in that major city. Today Ms. Clarke is here to share with us their findings and suggestions after one additional year of working in what really, Mr. Chairman, is one of the finest programs in the country and one which can teach us a great deal about outreach.

Mr. WAXMAN. I thank the gentleman and want to join him in welcoming Ms. Clarke to the hearing today. We are pleased to receive your testimony.

STATEMENTS OF HAZEL CLARKE, HEALTH COORDINATOR, TRI-CITY CITIZENS UNION FOR PROGRESS; HOWARD M. PERLMAN, PRESIDENT, HSC SERVICES, INC.; AND PAULETTE POPE, CHAIRPERSON, BALTIMORE WELFARE RIGHTS ORGANIZATION, ACCOMPANIED BY ROBERT CHEEKS, EXECUTIVE DIRECTOR

Ms. CLARKE. Thank you, Mr. Chairman.

My name is Hazel Clarke. I am health coordinator of the tri-city health action program. I am pleased to be here today to present this testimony in support of outreach and as exponents of health care.

At this time I would like to share with the committee my personal encounter with outreach; 12 years ago, my neighborhood was canvassed by outreach workers from the Newark Preschool Council. Unfortunately that day I was not at home but my neighbor was. They talked to her about the program and what service was available to the children and families. She in turn told me about the program.

As a result of that discussion I enrolled my child. I participated in parents and board activities and at the time I was a welfare recipient.

As a result of my involvement I enrolled in college, graduated and now am self-supporting. I definitely believe in outreach. I believe that outreach was the beginning of my self-development.

I am now employed by an organization that is doing similar outreach work in the community. This organization is known as the Tri-City Union for Progress, Inc. It is a private nonprofit neighborhood development corporation operating since 1966. We work in a predominantly black and Hispanic community and provide child care, housing and health care for the residents of a 12-square-block area in the community of the central ward of Newark.

The community health education program that I am coordinator of began in January 1973 as a result of a grant received from the Florence and John Schuman Foundation. This grant enabled us to provide the children in the Tri-City educational program with com-

prehensive health screening services. These services have now been expanded to include all children in the community.

Our child health action project was set up to be a model child health conference station. The extensive health care services provided by Head Start provided a sound foundation. It was clear to us that early detection and health education for parents were the key to a preventive care system for children.

With that in mind, the following services are provided to children at our center: Developmental services include health history, taken in the language of the parent or guardian.

Examination of the entire body, height and weight, vision and hearing, nutritional counseling, laboratory tests, including TB, hemoglobin, blood pressure, PKU, immunization, PB, measles, rubella, polio, and mumps.

Our philosophy is that outreach is more than knocking on doors. To many institutions outreach means use of the newspapers to inform people of programs that are available. This method will only reach consumers who read the newspapers or organizations who must then spend time informing their clients. This method does not scratch the surface or reach medicaid eligible families. In New Jersey, the EPSDT program does send a notice to all welfare recipients informing them of their entitlement of child health services. However, there is little information available to recipients about why preventives services were important and what services can best help their children.

In our neighborhood we try to cover all possible angles. This concept is simple and works. First, our organization designated a target area. In our case, the target area is concentrated in 12 square blocks. There are approximately 7,000 people or 2,000 families in the target area. About 30 percent of the families are Spanish speaking.

Second, we recruited an outreach staff. This staff is comprised of six women who live in the neighborhood. At least two of the health workers must be Spanish. Most of the women were on welfare or unemployed before we hired them. They had never done outreach work before but had outgoing personalities and civil interests.

We call our staff health block workers and not just outreach workers, because we want to give the idea that health outreach is more than just knocking on doors.

Health education starts when that adult answers the door. Our health progress talks to the parents, whether the child has all of his or her shots, does the family have a regular doctor, does the child have any problem or behavior that bothers or confuses them. This leads the parents to think about prevention and our checkup clinic.

Since most people are crisis oriented they don't think of medical care until there is an ache or pain. This conversation helped to lead parents into detection and prevention thinking. If the child is not getting regular checkups, or is not up to date on immunization, the health block worker will try to get the parents to make an appointment at our clinic. If the parent has another source of health care we leave an outline of our lab tests and developmental tests they should request from their private physician or clinic. We urge them to get moving on getting checkups for their children.

In the statistics we have included in this testimony, you would note that our enrollment of nonmedicaid children is more than twice as high as medicaid enrollment. This is mainly because the services available to nonmedicaid families is free of charge. The city of Newark has a vendor payment contract with us to serve children of nonmedicaid neighborhood families.

Outreach doesn't end with making the appointment. The services that people encounter when they finally get to the center, which determine whether they come again. For that reason we try to make sure that our center staff is not only bilingual but is also community oriented. At the present time our center staff numbers eight. Of that number, four are of Hispanic origin.

Our consultant physician is African-American but speaks Spanish. To communicate we try to recruit for all positions from the neighborhood first. The atmosphere of the health center is intended to be professional but personal and sensitive to parents and their children. We use pediatric nurse practitioners who are especially trained to give counseling and time to parents. They are prevention oriented and recognize that parent is the main actor in health care for children.

As I have stated before, outreach is more than knocking on doors in our neighborhood. It is the way of life that is crucial for health care as well as physical and emotional development of young children.

In closing, here are some recommendations to share. One, CHAP must set a policy of encouraging the community participation in the planning and implementations of its program. Two, CHAP should provide incentives for State agencies that are effective and involving community based health services.

Three, costs of outreach should include as a legitimate part of the cost of care. State agencies that do so should be eligible for the maximum possible FFP. Four, training and development grants in contract in outreach techniques should be made available to experienced community organizations.

Thank you.

[Testimony resumes on p. 254.]

[Ms. Clarke's prepared statement follows:]

STATEMENT OF HAZEL CLARKE, HEALTH COORDINATOR, TRI-CITY CITIZENS UNION
FOR PROGRESS

THE WEST SIDE PARK NEIGHBORHOOD

A. Character

The West Side Park area could best be characterized as a neighborhood still in the state of flux that was precipitated by the exodus of white ethnic elderly people in the late 1960's and the influx of younger Black and Hispanic "refugees" from the inner core of the city. Residents of the central city were dislocated for the construction of a state medical school as well as other public institutions as part of the city's urban renewal program.

The predominantly Ukrainian population took with them that sense of community and economic stability that had characterized this western fringe area of Newark for forty years or more. Their offspring, now middle class and committed to suburban living, were not interested in living in the three family wooden frame building lined shoulder to shoulder in this neighborhood. Thus, the outgoing population left their homes, churches, public halls and businesses to an incoming population that was, for the most part, not prepared economically or socially for ownership.

West Side Park residents were hard hit by unemployment and inflation. Of the 17,200 residents, almost half (47%) are under the age of 18 years. The large minor population has a large high school drop out and concomitant unemployment rate. This combination of idle youth from disparate cultural backgrounds makes for a potentially explosive situation. It also increases the incidences of vandalism and crime in the neighborhood.

It was in the context of these problems that Tri-City Citizens Union for Progress began its neighborhood development work in 1967---

The Tri-City Citizens Union for Progress was formed in late 1966 by civil rights activists and clergy from the three urban centers of northern New Jersey: Newark, Jersey City and Paterson. Each city formed a local chapter to identify those needs unique to its own community and to decide on those activities that would best foster black self-development. The general objectives the Citizens Union established as a

three-city coalition were:

1. Economic development of the community
2. Preparation of children and adults for the world of work
3. Greater awareness of the cultural heritages of the community
4. Wider civic participation
5. General community rehabilitation

Within the next two years, the Jersey City and Paterson chapters foundered and died out. The Newark chapter, however, took hold of the idea of sponsoring housing rehabilitation and continued to grow. Within the ranks of the Newark members were people who had organized community controlled programs, clergy and most importantly a former national labor organizer whose negotiating skills and political acumen had been recognized in labor circles for over thirty years. The chapter never exceeded twenty members, but the combination of skill and determination was enough.

Within the first three years of its existence the Citizens Union for Progress:

1. sponsored the first state financed rehab project in New Jersey;
2. set up one of the first community sponsored reinvestment efforts by using \$30,000 of private money to leverage \$1.4 million dollars into the neighborhood;
3. negotiated the rehab of 700 more units of housing under private development. More than \$14 million rehab dollars were brought in;
4. organized one of the first low income housing co-ops in the state;
5. created jobs for a large number of minority workers;
6. gave minority contractors their first large scale construction work in the city;
7. arranged for low cost housing protected from absentee ownership;
8. generated funds to bring community services into the neighborhood;

The Community Health Education Program began in January, 1973 as a result of a grant received from the Florence and John Schumann Foundation. This grant enabled us to provide the children in the Tri-City Educational Program with comprehensive health screening services. These services have now been expanded to include all children in the community. Because of receiving the Foundation grant, Tri-City was

able to negotiate with the Newark Department of Health and Welfare to sponsor The Children's Health Action Project for a six (6) month period. A commitment was made to continue funding when more funds were available. Tri-City has also been approved as a medicaid provider under the Early Periodic Screening Diagnosis Treatment Program. With monies received from this program we hope to be able to offer services to even more children, thus a private grant has now helped to generate on-going public funding.

I. Review of General Objectives

The five major objectives of the Community Health Education Program:

1. By the use of Block Health Workers, to see that every child and woman in our designated 12 square block area receives comprehensive health screening, counseling and follow-up;
2. to provide health services to children enrolled in the Tri-City People's Center;
3. to sponsor community health education programs that emphasize preventive health care;
4. to organize action for upgrading health services and revamping policies; and
5. to sponsor an on-going program of community outreach, education and follow-up.

II. Specific Objectives

1. To provide a community education and health screening program emphasizing nutrition, accident and poisoning prevention and mental health;
2. To provide children's health screening programs in the 12 square block area that includes:

- vision	- dental referrals
- speech	- lab tests
- hearing	- treatment for minor illness
- counseling	- immunizations
3. To extend services to neighborhood day care centers that don't have provisions for health services in their budget;
4. Influence public school health in 12 square block area;
5. Educational and training sessions for parents, staff and community people will be conducted by the practitioner.

III. Scope of Services

Our Children's Health Action Project was set up to be a model child health conference station. The extensive health care services provided by Head Start provided a sound foundation. It was clear to us that early detection and health education for parents were the keys to a preventive health care system for children. With that in mind the following services are

provided to children at our Center:

*Developmental:

Health history taken in the language of the parent or guardian

Examination of the entire body (unclothed)

- Height and weight
- Vision
- Hearing
- Speech
- Nutrition Counseling

*Lab

*Immunizations

- TB
- Lead
- Hemoglobin
- Blood Pressure

- DPT
- Measle
- Rubella
- Polio

OUTREACH IS MORE THAN KNOCKING ON DOORS ---

To many institutions, outreach means use of the newspaper to inform people of programs that are available. This method will only reach consumers who read the newspaper or organizations who must then spend time informing their clients. This method does not scratch the surface of reaching Medicaid eligible families.

In New Jersey, the EPSDT program does send a notice to all welfare recipients informing them of their entitlement to child health services. However, there is little information available to recipients about why preventive services are important and what services can best help their children.

In our neighborhood we try to cover all possible angles. The concept is simple and works.

First, our organization designated a target area. In our case, the target area is concentrated in 12 square blocks. There are approximately 7,000 people or 2,000 families in the target area. About 30% of the families are Spanish speaking.

Secondly, we recruited an outreach staff. This staff is comprised of six (6) women who live in the neighborhood. At least two of the Health Block Workers must be Spanish speaking. Most of the women were on welfare or unemployed before we hired them. They had never done outreach work before but had outgoing personalities and civic interest.

We call our staff Health Block Workers and not just outreach workers because we want to give the idea that health outreach is more than just knocking on doors. Health education starts when that adult answers the door. Our Health Block Worker talks to the parent about.

whether or not the child has all of his/her shots. Does the family have a regular doctor? Does the child have any problem or behavior that bothers or confuses them? This leads the parent to think about prevention and our check-up clinic.

Since most people are crisis oriented, they don't think of medical care until there's an ache or pain. This conversation helps to lead parents into detection and prevention thinking.

If the child is not getting regular check-ups or is not up to date on immunizations, the Health Block Worker will try to get the parent to make an appointment at our clinic. If the parent has another source of health care, we leave an outline of the lab tests and developmental tests they should request from their private physician or other clinic. We urge them to get moving on getting check-ups for their children.

In the statistics, we have included in this testimony, you will note that our enrollment of non-Medicaid children is more than twice as high as Medicaid enrollment. This is mainly because the service is available to non-Medicaid families free of charge. The City of Newark has a vendor payment contract with us to serve the children of non-Medicaid neighborhood families.

Outreach doesn't end with making the appointment. The service that people encounter when they finally get to the Center will determine whether they will come again.

For that reason, we try to make sure that our Center staff is not only bilingual but is also community oriented.

At the present time, our Center staff numbers eight (8). Of that number, four (4) are of Hispanic origin. Our consulting physician is Afro-American but speaks enough Spanish to communicate. We try to recruit for all positions from the neighborhood first.

The atmosphere of the Health Center is intended to be professional but personal and sensitive to parents and their children. We use Pediatric Nurse Practitioners who are especially trained to give counseling and time to parents. They are prevention oriented and recognize that the parent is the main actor in health care for children.

Outreach is more than knocking on doors in our neighborhood. It is a way of life that is crucial to health care as well as physical and emotional development of young children.

For that reason, we have become more and more alarmed at the cutbacks in human services at a time when this country should be investing more money and resources into the development of our children. It is troubling that in this International Year of the Child that health experts are concerned about the large number of children both poor and well off who are suffering from nutritional deficiencies.

Children have more cavities these days--largely due to high concentration of sugar in their diets.

Children are having a variety of behavioral problems, some emotionally and others physically caused.

Children are less protected from early childhood diseases whose cures have long been established.

All of these problems point to a serious gap in our health care system. We have a vast, well oiled, health treatment system that all Americans cannot afford.

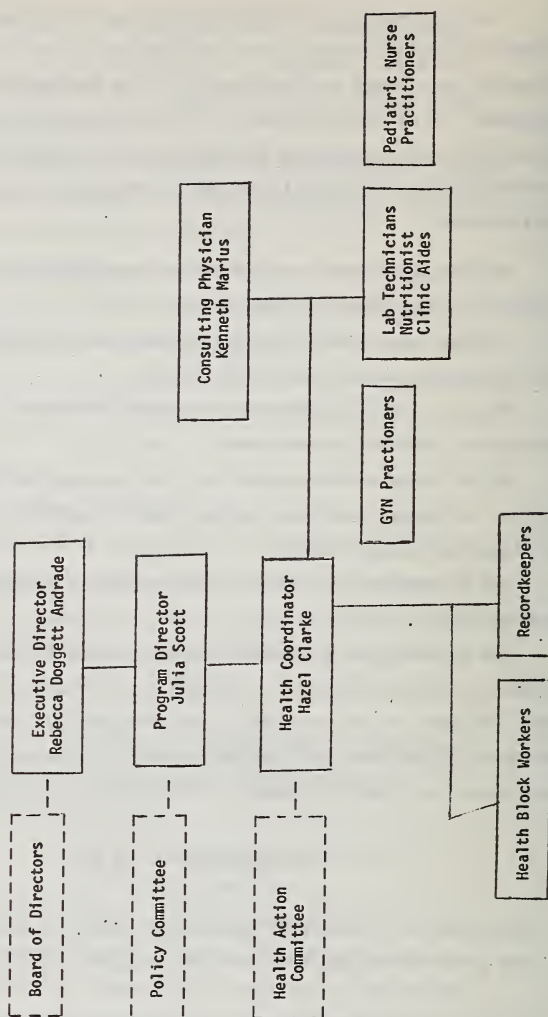
And to make matters worse, we do not have a preventive health care system at all.

The Child Health Assurance Program is about prevention and it is about child development. Most babies are lucky enough to be born well. We have to put more effort into keeping them well. A good wellness program puts the responsibility in the hands of parents. Health care providers are really the educators and coaches.

Recommendations for CHAP

1. CHAP must set a policy of encouraging community participation in the planning and implementation of its programs.
2. CHAP should provide incentives for state agencies that are effective in involving community based health services.
3. Costs of outreach should be included as a legitimate part of the cost of care. State agencies that do so should be eligible for the maximum possible RFP.
4. Training and development grants or contracts in outreach techniques should be made available to experienced community organizations.

Tri-City Citizens Union for Progress, Inc.
Newark, New Jersey
Health Organizational Chart



CHILDREN'S HEALTH ACTION PROJECT
Tri-City Citizens Union for Progress

CLINIC ENROLLMENT				
YEAR	1976	1977	1978	1979 (1st Quarter)
MEDICAID	112	543	419	83
NON-MEDICAID	424	870	1,090	270
TOTALS	536	1,413	1,509	353

CHILDREN'S HEALTH ACTION PROJECT
Tri-City Citizens Union for Progress

APPOINTMENT STATUS REPORT			
YEAR	1977	1978	1979 (1st Quarter)
APPOINTMENTS MADE	2,041	2,054	561
CANCELLATIONS	52	107	14
RESCHEDULES	166	174	44
NO SHOWS	576	398	144
APPOINTMENTS KEPT	1,413	1,509	403

WOMEN'S HEALTH ACTION PROJECT'S
Appointments Status for 1977 - 1978 - 1979

	1977	1978	1979
APPOINTMENTS	483	959	262
CANCELLATION	123	170	50
NO-SHOW	103	295	47

*1ST QUARTER OF 1979

Mr. WAXMAN. Thank you very much. We appreciate your testimony.

Before we hear from Mr. Perlman, we are being summoned to the House floor for a vote. I think this will be a good time, before you start your testimony, to break for about 5 minutes so we can go to the floor and vote.

[Brief recess.]

STATEMENT OF HOWARD M. PERLMAN

Mr. PERLMAN. My name is Howard Perlman and I am president of HSC Services, Inc. with offices located in Denver, Colo. I would like to extend my appreciation to Chairman Waxman, to Dr. Carter and to other members of the subcommittee for providing me with the opportunity to address you on the subject of child health screening programs.

I do not appear before this subcommittee to comment upon a particular child health assessment program bill being considered, or to discuss outreach except as a component of our entire program. Rather, I appear before you as the president of HSC Services, Inc., a company which has worked closely with our consulting nonprofit corporation, Health Screening Research Foundation—HSRF—to administer the State of Pennsylvania EPSDT program for the past 5½ years.

I believe it would be useful to focus upon many of the issues we have addressed in administering this program.

The Pennsylvania EPSDT program is considered by many as one of the finest, if not the finest, children's programs in the country. The Health Care Financing Administration of the Department of Health, Education, and Welfare is well aware of this program, and it is cited as a model for other States to follow. At the same time that it is recognized as a superior program, it should be mentioned that there has been no increase in medical costs to providers since its inception 5½ years ago, while administrative costs prompted very often by the State, have been reduced by more than 50 percent. This is a rather unusual accomplishment in the inflationary health care era in which we find ourselves.

How did this come about? How did it happen that one State could produce such a fine program while others floundered and are still unable to produce a viable program to meet the needs of their underprivileged children?

I believe the story is worth telling, if only to acquaint those in the new administration with the history of the development of this successful program. It is interesting that hardly a single person—only one to our knowledge—is still with the State of Pennsylvania's Department of Welfare who would have knowledge of the trials experienced in putting this excellent program together.

Initially, it was the Department of Welfare's intent to divide the State into three regions for the purpose of evaluating the possible advantages that might occur to the State from divided authority.

The western region was to be run by a proprietary corporation, the central region by the Department of Welfare, and the five-county eastern region by a nonprofit corporation. The purpose of divided authority was to determine which would operate to the best

advantage for the State's EPSDT participants while producing a cost effective program.

The initial bid of HSC Services, Inc., a proprietary company for administration of the western division, was considerably lower than the next lowest bid by the Westinghouse Corp. We were told that HSC's bid was almost one-half of their bid which created considerable consternation on the part of HSC's executives. A review of our cost figures substantiated our bid.

Shortly before the contract was signed, an attorney for the State of Pennsylvania's Department of Welfare uncovered a clause in a State regulation that stated, "The Department of Welfare may contract with a nonprofit corporation." This was interpreted literally to mean only with a nonprofit organization. HSC was requested to form a nonprofit corporation. Fortunately, HSC had previously initiated such a corporation, the Health Screening Research Foundation, at the request of officials of HEW.

The purpose of this foundation was to receive Federal grants in the field of health testing. A new contract for the western division was then signed between HSRF and the Pennsylvania Department of Welfare. The regulation requiring the department of welfare to contract with nonprofit organizations has since been rescinded.

I am going to skip part of this in the interest of time and at the same time, with apologies to the reporters, I am going to try to answer as I go along some of the questions that were raised by members of the committee with regard to how we solve some of the problems that were asked.

Initially there was a great deal of opposition from both the medical profession, which, through the Pittsburgh medical group, had hoped to secure the administration of the program, and from local welfare rights organizations.

At the start of the operations, there was not a single physician or provider group that willingly endorsed the EPSDT program. Today, after considerable cultivation and public relations work, Health Screening Research Foundation staff has certified over 600 providers and utilizes the services of more than 450 providers with over 1,000 physicians.

The welfare rights organizations, which had previously initiated court actions against the State, now have the greatest respect for HSRF and its staff for the manner in which they have treated participants and their relationships with providers.

As an example, all children are handled by appointment only. Parents are visited to check on the treatment received by the children.

How was this accomplished? In the first instance, although the medical profession in Pittsburgh appointed a committee to work with HSRF, it actually was a deterrent to the implementation of the program. They threw many a roadblock in the program by endeavoring to dictate policy, forms, pay structures, et cetera. Rather than continue to hold up the program's implementation, those executives of HSRF responsible for the administration of the western division boldly took steps in opposition to the newly formed medical committee and implemented certain standards which health care providers were obliged to comply with. With the cooperation of the Pennsylvania Department of Welfare officials,

the entire program was implemented and, fortunately, proved to be extremely successful.

One element of this program was the introduction of HSRF of history and physical examination forms, some with as many as 50 questions, that required a sincere effort on the part of providers to complete. Although this type of history and physical examination was originally opposed, in the final analysis as it forced standards upon providers in the methods of performing examinations and taking histories. Interestingly enough, when the American Academy of Pediatrics published its "Guide to Screening" for HEW, the suggested history form followed very closely the idea promulgated by HSRF.

In the last year, a simple form, which we opposed, was utilized by the State. It fails to follow, in our opinion, certain patterns of history in examination and doesn't give us the ability to review their activities as well as the previous forms.

The administration of the program began slowly, but eventually proved its viability to the extent that the department of welfare, which was unable to initiate its own program for the central division, asked HSRF to undertake the administration of that area as well. Later, when the Philadelphia contractor experienced difficulty in reaching its goals, HSRF provided consulting and training assistance.

Because HSRF believed firmly that, as a contractor for the State, we had a responsibility to provide the finest care possible for the children, we initiated a series of steps to guarantee quality care.

First of all, HSRF certified all providers as to the medical background, staff, facilities, equipment, et cetera, including requiring all providers to purchase audiometric test equipment. Over and above the requirements of the contract, HSRF established a monitoring system through staff observation and computer controls that monitors the EPSDT activities of the providers. Evaluation results from this system can determine whether a provider has too many immunizations given or not enough, as well as the quality of these tests as compared with every other provider in the community and in the 62 counties.

Through this system, HSRF can spot both overutilization and, in particular, underutilization and bring these deviations to the attention of the providers. HSRF also sends nurse observers periodically into each provider's office. Through these techniques, which we developed on our own, HSRF has been able to eliminate those providers who have failed to render quality service.

At this point, I would like to inject that Ms. Mikulski asked a question as to what happens with the providers and referral. We follow the children until they have been screened completely and until they have been treated and the county board of assistance receives each month a listing of those children who are eligible for screening that month as well as every 30, 60, 90, 120 days for those children who have not yet been referred for treatment.

In addition, we provide each provider with a list of specialists so that when they refer a child or have a reason to refer a child, they are given a list of specialists who will treat that child in that specialty within their community or within their region.

How do we manage this strict control of the providers' activities? As mentioned above, we did it with the cooperation of the State of Pennsylvania Department of Welfare. We studied the problems faced by providers in operating within the medicaid and medicare programs and learned where the problems were, why competent providers left the program and why, in many instances, the less qualified remained. We found that in most instances the providers were not paid on time—sometimes 6 to 8 months after billing—were not told why they were not being paid if an error occurred, and were confused and deterred by the billing system. Thus, we had to solve those problems if we were to make EPSDT successful.

We prevailed upon the Pennsylvania Department of Welfare, as an exception to the State's method of payment to medicaid providers, to permit HSRF to bill on the behalf of the providers. This required HSRF to receive and verify the completed screens from which a provider invoice was created. These were checked both visually and by computer.

We also arranged with the State to pay providers as close to 30 days after the end of the month in which screens were completed. The above proved so successful that it was continued in succeeding years and as a result, brought many previously opposed providers into the State's medicaid system.

Where no providers were available, and there were times in certain counties where county medical societies refused to participate, we sent strike teams into the area to take care of those children, and it was surprising how many doctors then joined up.

This quid pro quo, our doing something for the providers, gave us an opportunity to ask much of them in the way of monitoring their activities and controlling costs. The State has not had to increase its EPSDT costs to providers since the initiation of the program some 6 years ago. At the same time, HSRF has gradually reduced its administrative costs by 50 percent.

HSRF initiated and implemented many additional components within the structure of the EPSDT program that effectively contributed to the success of the State's program. A brief review of some of these components is in order.

PROVIDER RECRUITMENT AND RAPPORT

By utilizing field reps, HSRF has built an excellent rapport with the medical community. In building this rapport, HSRF has served beyond contractual obligation by performing the following tasks:

First, visit a new provider on his first day of screens in order to give advice on patient flow, help with paperwork, and provide moral support.

Second, provide transportation for screening in private vehicles and frequently on the field rep's own time when the county is unable to provide this service during evening and weekend hours.

Third, serve as liaison between a new provider and the State of Pennsylvania Welfare Department in obtaining a medicaid billing number—saving the several months it usually requires to get this number.

Fourth, serve as liaison between providers and State health department when problems occur in obtaining free vaccines.

Fifth, assist providers and specialists in solving problems with medicaid billing.

Sixth, assist providers in recontacting families for completion of incomplete screens.

Seventh, hand-carry provider invoices to the State in order to save time and speed up check delivery.

CBA RAPPORT

The Health Screening Research Foundation's rapport with the county boards of assistance is excellent. Here again, HSRF has performed tasks not required by contract:

First, field reps contact and cooperate with allied agencies in order to recruit children under their care into our program.

Second, HSRF developed manuals and paper flow systems for the CBA's—MEF has been developed for all counties through our experience in Allegheny County.

Third, HSRF developed the "Strike Team" concept—specialists in outreach techniques and internal CBA systems visited and worked with counties having problems.

Fourth, HSRF developed systems for county management of followup care even though the manual states followup care is the "sole responsibility of the CBA."

Fifth, HSRF developed a complete resource center for the phase V followup system through the use of the referral activity report.

Sixth, HSRF developed the "Mock-Audit" concept—specialists in Federal regulations visit counties and study cases pulled at random to determine how well the county is complying with Federal regulations. Based on the result of this trial audit, HSRF suggests changes as necessary to bring the county into compliance.

BENEFITS TO COMMONWEALTH

First, because of HSRF's efficient billing system, incomplete screens are not passed for billing.

Second, HSRF has developed special reports to State health department on immunizations.

Third, HSRF provides an EPSDT provider list to the State health department so they can report to Washington how many physicians requesting free vaccines are providing EPSDT service.

MAMIS—TRAINING PROVIDERS ON NEW BILLING SYSTEM

First, HSRF has updated for the State their own provider list to make it a workable item.

Second, HSRF has scheduled all seminars for MAMIS training.

Third, HSRF has trained all providers on the new billing system. HSRF has developed a seminar presentation making transparencies for overhead projectors.

Fourth, podiatrists are now using new forms with minimal errors because of HSRF's training program.

MISCELLANEOUS

HSRF developed the one-part form and a new data system to go with it. This form has made EPSDT more attractive to providers. HSRF trained over 500 providers on the use of this form in approximately 1 month.

HSRF developed a mobile screening package for areas with a medical provider shortage.

HSRF's quality control system includes: (a) Data checks, (b) RN visits, (c) computer scans.

It should not be overlooked that HSRF played a paramount role in assisting the State of Pennsylvania to relieve itself of its court-ordered obligations. We promised State officials to attain certain goals which were accepted by the court in the initial action. HSRF's officials and staff worked diligently to provide the State with sufficient screens to meet the court's mandated quotas. Failure to meet that obligation would have created adverse publicity, and cost the State hundreds of thousands of penalty dollars. We feel justified in taking large credit for preventing the above and upholding the State's integrity.

Each year, HSRF capably carried the program by providing large sums of money in order to continue its administrative activities. This was necessary in order not to have a letdown in screens when, during the last months of each fiscal year, the State of Pennsylvania was unable to meet the financial demands of its programs. This could have compromised the State's efforts to comply with the court order if HSRF had not provided the funds to carry out its functions.

In conclusion, let me say that I have reviewed the three CHAP bills proposed for the assessment and care of children with a great deal of interest. Not only is there a great need for what you are endeavoring to accomplish, but there is a great deal that can be done. I sincerely believe that only by improving both the health and educational capacity of those children deprived of certain advantages due to low levels of family income, can we break the poverty or welfare cycle which is causing an outlay of billions of dollars to welfare programs.

However, I must tell you most emphatically that unless you are willing to mandate certain actions such as those which I have previously described on the part of the States and their providers, implementation of CHAP legislation will run into the same pitfalls as have befallen the EPSDT program for which great hope was held when it was first passed by the Congress.

Thank you very much.

Mr. WAXMAN. Thank you very much. We appreciate your remarks.

I will now call on Paulette Pope, chairperson, Baltimore Welfare Rights Organization.

STATEMENT OF PAULETTE POPE

Ms. POPE. Chairman Waxman and members of the subcommittee, my name is Ms. Paulette Pope, I am chairperson of the Baltimore Welfare Rights and am also a welfare mother. I am glad to be here

today to speak to you concerning the EPSDT in CHAP and outreach and how to make it work.

The Baltimore Welfare Rights—BWRO—appreciates the opportunity to appear before the subcommittee to express our views on the child health assessment program—CHAP. In this Year of the Child, CHAP is of special importance to us all.

BWRO is a private, nonprofit organization of welfare mothers and their families. We first became involved with children's preventive health screening issues almost 1 year ago, when 60 BWRO members and welfare mothers attended a 2-day conference on EPSDT sponsored by the national economic development law project.

Before the conference, not one of us knew that EPSDT was available for our children. But it is not hard for a mother to recognize the importance of a program which protects her child's health. After the conference, BWRO made EPSDT one of its top priorities. Since then, we have been very active in trying to make the program work for our children. BWRO members have visited local welfare offices, health maintenance organizations, and the city health department, finding out how the program works and what people are told about it. We have negotiated with the welfare department and with the State department of health and mental hygiene. We have served on a health systems agency subcommittee investigating outreach needs.

We are here today to speak from our experience and to express our support for the work this subcommittee is doing on CHAP. In particular, we are here to underline the importance of outreach, and to urge that the subcommittee support a bill which, one, requires States to earmark a certain portion of the program budget for outreach and, two, requires the use, whenever possible, of nonprofit community-based organizations as providers of outreach and followup services.

In this I would like to say that in working in outreach we feel very strongly that welfare mothers and poor people are the best in getting to people and letting them know about the programs and getting their understanding, bringing them up to where they will get involved and get their children involved in the programs.

THE IMPORTANCE OF OUTREACH

We know from our experience that outreach is important. As welfare mothers, we care about our children's health. We see children in our neighborhood with health problems that could have been prevented by screening and early treatment. We know of children labeled slow and put in special classes when their real problem is that they cannot see or hear well enough to do their school work. We are convinced of the importance of preventive health care for our children.

But EPSDT is one of the best kept secrets in Maryland. Last year, only 12 percent of the eligible children in Maryland were screened under EPSDT. It was not that the mothers of the other children did not care. They did not know that EPSDT existed. When BWRO found out about EPSDT, we found out about it from a group in California. Some of our mothers have been welfare

recipients since EPSDT began, but not one of us could remember being told about it by our welfare worker.

In most cases when you go into DSS and you have papers put before you, the papers are not explained, you are just told to sign and fill the papers out as swiftly as you can in order for you to receive any moneys from the State. So any services you are hesitant to inquire about because if you do, you would find that the response with the workers is cold and despondent. They want to urge you out of their offices because of their overcrowded, overloaded case work, so they don't have time to go into anything in detail, so, therefore, it is just "check no, sign your name" and go from there.

WHY OUTREACH IS NOT WORKING

Our experience in Maryland is a good example of why the current outreach requirements are not enough. In Maryland, the State tells people about EPSDT in two ways: First, when it mails people their medical assistance cards it includes a written notice about EPSDT.

Second, when people apply for aid to families with dependent children—AFDC—they are given a brochure and asked to sign a statement saying whether they want to find out more about EPSDT. If they say they want a detailed explanation of EPSDT, they are supposed to be given an appointment with a service worker who will explain the program. This does not happen and mothers are not informed about EPSDT.

According to the Department of Health, Education, and Welfare, Maryland's outreach program meets the current legal requirements. These requirements are not met. Outreach is not working. Many welfare mothers have trouble reading, so they do not read the written notice, or they do not understand what it means.

Since our workshop last year, we have tried to find out what really happens in the welfare office when people apply for assistance and are supposed to be told about EPSDT. What often happens is that the worker will fan out a lot of papers, such as I mentioned before, and tell the applicant to "just sign these and check no; you don't need this program." People applying for welfare are often scared that they will not get the money they need, so they do what the worker tells them to. They never even get to read the paper telling them about EPSDT.

If applicants do check that they want to know about EPSDT, they are supposed to be given an appointment to see a service worker who will explain the program. But this means making a second visit to the welfare office, arranging for child care, paying a second busfare, and often waiting all day to see the worker once you get there. Often it takes 2 weeks to get an appointment. And often the worker does not know about the program.

A few examples are the following: One BWRO member called her service worker and said she wanted to get EPSDT for her children. The worker had never heard of EPSDT, so the mother had to explain what the program was. When the mother finished, the worker asked if her children were sick. The mother said no, that she wanted EPSDT to keep them from getting sick. The worker

replied that she had too much work to be bothered if the children were not sick, and hung up.

A second example is a group of BWRO mothers who went to another welfare office to find out about EPSDT. They asked every worker about the program, but not one knew what it was.

One pregnant teenager mother went in to apply for AFDC. A member of BWRO went along to help her out, and asked if the teenager could get EPSDT for herself. The welfare worker told her that EPSDT was only for children under 12 and the teenager was not eligible.

BWRO mothers went to another welfare office to find out where their children could get EPSDT screening. No one in the welfare office knew.

WHAT OUTREACH SHOULD INCLUDE

CHAP will only work if it reaches the children. Face to face, outreach by community based organizations can help make CHAP a reality. Written notices are not enough for effective outreach, especially if mothers cannot read them. There are quite a number of mothers that can't read so, therefore, they don't have any knowledge. They are quite ignorant as to what is available for them.

Successful outreach must include personal contact. Face to face outreach is important so that the outreach worker can explain the program to the mother and help deal with any problems about it. I was relating to that before. A welfare mother can relate to another welfare mother on a much more relaxed basis because she will confide to another welfare mother about the problems she has before she will a professional because often when a professional comes to your home they feel very nervous, very despondent because they don't feel like they are really there to help them, only just to haunt them or get on them about something. So they will right away back off from anything.

A welfare mother can deal with this with another welfare mother because of her own self experiences, because of her own existing problems, so, therefore, they have a relationship of understanding because of both living in the same type of life style.

The mother may not understand why preventive screening is important. She may be afraid that the program costs money she does not have, or need help arranging for transportation or child care. Personal contact is the only effective way to answer those fears and to eliminate barriers to participation.

Personal contact should include contact by members of the poor community wherever possible. If a welfare worker comes to your door in a poor community, you are afraid. You want to know what you have done wrong, and you are not likely to hear what he or she is saying to you about preventive health screening. Maybe the worker uses big words you do not understand. Or maybe you do not have car fare to take your children to the clinic, but you are too ashamed to admit it and the worker does not think to ask.

Maybe you don't understand what the doctor is telling you once you get to the clinic, but you are afraid to bother him and there is no one you can ask to help you find out what your child needs. You

need someone who shares your experience and speaks your language to help you get the most out of the program.

We believe that community based groups can do the most effective outreach. Groups like BWRO come from the poor community. We have the trust of people in the neighborhoods. We poor people are much more likely to let other poor people inside our doors than we are to listen to even the best intentioned professional. Groups like Baltimore Welfare Rights Organization have already demonstrated a commitment to serving the poor community. We will be effective because we care.

We are pleased that Congress is moving on children's health legislation this year, and appreciate the subcommittee's attention. We are optimistic about our children's health and their future, and hope that any recommendations which come out of this subcommittee insure that CHAP will reach our children.

I thank you for giving me this time and if there are any questions, I would be more than glad to answer, and I have several people with me here today to help if I can't.

Mr. WAXMAN. Thank you very much. Your statement has been very helpful to us.

Ms. Mikulski?

Ms. MIKULSKI. Thank you, Mr. Chairman.

Miss Pope, I have a few questions for you. I would like to note that Miss Pope is accompanied by other members of the Baltimore Welfare Rights Organization, and the legal aid lawyer, who has been very active and helpful to them.

Miss Pope, on page 2 of your testimony you talk about outreach groups and you go on in another part of your testimony to talk about using welfare mothers or other poor people to reach out to the community.

My question is this: Would it be better to contract with groups such as the Baltimore Welfare Rights Group or what do you think of the idea of the welfare department hiring welfare mothers to reach out on this program and perhaps any other, like to explain food stamps or whatever?

Do you think it is ultimately more effective to reach out to other welfare recipients by, one, making employees of welfare mothers or, two, by contracting it out to a community organization?

Ms. POPE. I feel that welfare mothers would be more relaxed in working with the community organizations because of their feelings toward us, their caring. They are taking the time to build up our knowledge as to what is out there for us and how best to use it.

I believe that such organizations would have training programs that would help us relate to other people in our conditions. I feel that very strongly. I don't feel working with the welfare department would answer it because in my opinion they shut off our access to information to begin with.

So if we were put in a position to work with them, I am sure it would be a cold, despondent relationship because really, they don't really know our problems because they don't live our problems so therefore they don't take the time to understand them.

Ms. MIKULSKI. You feel you would be more effective, taken more seriously, and be able to play a role of advocacy and information by a community organization?

Ms. POPE. I certainly do.

Ms. MIKULSKI. That takes me to the next question. What is a community organization, community group?

One of the problems we experienced in the poverty program with third party contracts was that voluntary agencies, that never wanted to serve the poor to begin with, when the bucks were around, they wanted to get in on it.

I mean no disrespect to United Fund agencies throughout the country, but they vary in terms of their sense of commitment and advocacy to the poor. I find some are rather traditional and even stuffy as they approach poor constituencies.

My concern is that the bucks would be captured by agencies that had no previous commitment and that grassroots community organizations, like the parents group out of the Mississippi Delta that started that first Headstart program a number of years ago that was so creative, wouldn't be able to get the bucks and the very agency that wanted to keep Fannie Lou Hammer in her place would be the ones that want to get the money.

Do you have any suggestions? Some of us who are committed to outreach would like to see the money go to the grassroots organizations and not to those that would like to see this money go to pay other administrative costs.

We can leave the record open. Would you agree that that is a problem?

Mr. Chairman, this is Mr. Robert Cheeks, executive director of the Welfare Rights.

Mr. CHEEKS. Yes, we do agree that that is a problem. When we refer to community-based organizations, we are talking about similar to Welfare Rights where 11 of the 13 member board, executive board of directors, are low-income people, people on public assistance.

We are talking about, we are also concerned that when the bucks start passing, that is a Freudian slip, but when the bucks are in existence—

Ms. MIKULSKI. The bucks have been passing, that is why Maryland is 49th in the program.

Mr. CHEEKS. But we are concerned that other groups now are going to start emerging and characterize themselves as community-based groups. But the groups that we are talking about are groups that have the, as our chairperson related, that have the trust of the community, and also if you go into the community and you talk to welfare recipients or persons who are eligible for this program and ask them what groups do they relate to when they have problems.

Now the other thing, Congresswoman Mikulski, when you mentioned the need for advocacy in relationship to community-based organizations, we feel that is going to be an ongoing need, it is an ongoing need for advocacy, advocacy to improve the quality of the program.

When we talk about community-based programs, we are not talking about simply community-based service programs. We are talking about programs or organizations that have as part of their function the characteristic of advocacy.

So that is the definition.

Ms. MIKULSKI. Do I have time for one more question?

Mr. WAXMAN. Surely.

Ms. MIKULSKI. Mr. Perlman, your testimony was—enlightening was not the word. It was absolutely stunning in terms of what you were able to do in Pennsylvania because you are 3 miles from Maryland. You were so effective and we were such a dismal failure.

I was wondering, how could you do all that I know you did, for example, the things that you outlined on page 5, and still provide a service and still make a profit? A State such as mine, with its close proximity to Washington, where they can't say they didn't have the information available to them, where we have a reasonable transportation system, if not an effective one, well, we are 49th, only above Alaska.

How did you do it and how did you make a buck?

Mr. PERLMAN. We did. As I pointed out, the State kept cutting down our bucks. I think we took a very strong attitude toward the entire program. In fact, for your information we have been trying to work with the department in Baltimore for the last 4 years and have made many suggestions to them.

I understand that they finally did put out a request for proposal along the lines that an outside organization, a third-party organization, would come in and assist them in the developing of a program that these people are looking for.

I don't know when that will take effect.

Ms. MIKULSKI. It takes effect when you give me all the recommendations that you have been giving them and I call up the secretaries and all. How were you able to do this?

Mr. PERLMAN. I can only tell you, it comes from administrative know-how and management and hiring the right people. We had many experiments in getting this thing properly organized and oriented, facing the problem of outreach, as an example.

We made a number of mistakes. We brought people in from the welfare rights organizations on our initial outreach programs. But we found that we had to set up special training programs for them, that even though they do have that rapport with their neighbor, they could not explain the programs until they themselves were properly trained in knowing what the answers were and how to handle it.

We set up a program on outreach as an example in which the people must be visited, I think it is two or three times, and a number of phone calls must be made.

We provide the county boards of assistance with a monthly list of those people who are that month eligible for screening. We provide them with all kinds of lists for followup.

The efficiency of the operation is such that I can't explain other than the fact that we use some management techniques that had never been used, I think, in the welfare programs.

Ms. MIKULSKI. What it seems that you had a goal absolutely to make this program work. You were committed to that, absolutely committed to that. Then you brought in a variety of other management techniques, accountability mechanisms and so on to make that happen, and it did.

Mr. PERLMAN. That is all I can say. I can't enumerate all the steps we took all the way along the line. You see, I have felt for a long time, and perhaps I am out of line and maybe it is a good thing that Dr. Carter isn't here, but that the administration of medicine is too darn important to leave to the hands of the doctors.

Ms. MIKULSKI. You are talking to the civilians from that world.

Mr. PERLMAN. We have been fighting that battle for a long time. We have been in the health field for about 10 years now. My previous experience is as president of two insurance companies, life and health and accident. I have had for years an avocation of reducing health and medical costs and improving the quality of care. The children's area came after our general organization for industry and Government agencies.

It is just a matter of finding that there are many management techniques and administrative know-how that you can apply to a health system which we have for some reason or other—some States have a fear that proprietary organizations should not have anything to do with welfare or with health.

We don't feel that way.

Ms. MIKULSKI. Could you tell me what HSC stands for?

Mr. PERLMAN. Originally it was health screening centers which was a form of health testing which we did for government agencies, organizations, Indian reservations, et cetera. But we have gotten away from just the testing. We do a great deal of computer work and programing for industry and government agencies and have gotten into administration programs. So we just use the initials now.

Ms. MIKULSKI. Thank you very much.

Mr. Chairman, I have no other questions.

Mr. WAXMAN. Could you tell us how many of the kids that you screened have been followed up on?

Mr. PERLMAN. I am not sure of the percentage, but it is very high, particularly in the dental area which we have found and which I should have commented on because I know there were some questions on the dental area.

When we couldn't find dentists to take care of the children, with the State's cooperation, in fact at the State's insistence, we built a mobile dental unit and we staffed it and sent it in to take care of them.

I think our figure is 87 percent. Mr. McKittrick who is also here from Pennsylvania may be able to give you some statistics. Ninety percent of the children have been screened. Our part of it is somewhere in the neighborhood of 8,000 to 9,000 children a month.

We do follow them up. We don't let them go until they are treated. They are on our computer records whether it is 30, 60, 90 or 120 days down the line.

Whether it is one or many referrals, the county boards get a listing of those children who have to be followed up.

Mr. WAXMAN. Mr. Leland, do you have any questions?

Mr. LELAND. I have no questions. I would like to commend the Welfare Rights Organization for participating in this area. As one who has been a strong advocate of outreach for many years, I would just like to say that I appreciate what you have done for us here, today.

Mr. WAXMAN. Mr. Maguire?

Mr. MAGUIRE. Mr. Perlman, I wonder on page 11 if you can tell us what certain actions you would mandate? You make a reference which takes us back to undetermined points earlier in your statement. I wonder if you could tell us specifically what you are referring to?

Mr. PERLMAN. I think in order to have an effective program in health we have to monitor very carefully the activities of the providers. We have to control their activities and in such a manner as to control costs.

We cannot promiscuously allow a provider to do anything he wants with the children. When I talked about the original history and pattern of examination that we created for him, we mandated that he had to ask certain questions in his history.

We also mandated that he follow a pattern of examination. That was to prevent fraud as much as you possibly could. This is one of the big problems. Many doctors skip over many of the important aspects of an examination. We have to do that kind of a thing. We have to be willing to, at the same time, to treat the doctor as a human being and understand what his problems are.

In most cases you find that the reason the good doctors dropped out and you had what you call medicare and medicaid mills is because there is a correlation between the dishonest and incompetent physicians. The only way to eliminate those is to control their activities. You can't control it by one or two cases. You have to understand what a pattern of medical behavior is or in some cases a pattern of medical misbehavior. You have to present them with the facts.

We have dropped about 15 physicians out of our program and there has not been a single complaint. Many have been dropped out by not sending any more patients, not sending any more children.

In one instance we found one physician who had too many earaches. He had far more earaches than average which meant he was going to get extra money for treating all those earaches.

We said, doctor, you are finding a lot of earaches. We would like you to write a paper on why you are finding so many more than anybody else. That stopped it immediately.

By monitoring this medical behavior you can control their activities and control costs.

I think it is time the States and Federal Government that have been paying this money for health care took a stand to mandate how that money is to be spent.

I hope I have answered your question.

Mr. MAGUIRE. Is that inclusive of the certain actions that you want mandated?

Mr. PERLMAN. Yes, sir.

Mr. MAGUIRE. What percentage of the eligible children actually end up in the program?

Mr. PERLMAN. I believe 90 percent of the children in Pennsylvania are being screened now. Mr. McKittrick can probably answer that better than I because I have been away from the actual operations.

Mr. MAGUIRE. You have not told us anything about the outreach to the children. You have been telling us how you work with providers and I think that is very impressive. Perhaps you can tell us how you reach the children and comment on what you have heard from the panelists with you.

Mr. PERLMAN. We have had two basic outreach programs in Pennsylvania. One is with the county assistance boards, except Allegheny which is Pittsburgh. In the other 61 counties we have had to work very closely with the county boards of assistance and social workers.

By providing them, we keep an eligibility list in addition to the eligibility list the State keeps. We provide the county boards of assistance with a list of those children who are eligible to be screened. We go in and talk to them and hold meetings with the boards of assistance and the social workers to see that they get on the ball and get those children into the program.

In Allegheny County we started out on that basis but because of a very difficult situation and having a more urban population, the State provided additional funds for us to set up an outreach program which unfortunately has now been eliminated because the State felt the cost was prohibitive. I am not too sure that it was in our area, but they have decided that.

In that program we hired about 30 to 40 people whose responsibility was to visit not once but as many as two and three times and the program was explained to them.

In addition, appointments were made for these people and we purchased three mobile units which went around and picked up the people when they themselves could not get into the doctor.

One of the things we did, and I think it had an effect upon the people, was that there was no clinic atmosphere in any of this. A doctor or a provider would say to us, we can take care of 12 children Wednesday afternoon. We would arrange for 12 children to be there at certain times so they could be taken care of.

There was no clinical atmosphere where the mother and child had to sit around for hour after hour waiting to be taken care of. We went back to the parents to see that they were treated in this manner. We were very insistent that whether the child was from a welfare family or whether the child's father was making \$100,000 a year, there could be no distinction in the program.

When the welfare rights people began to understand that we were treating them in this manner and our outreach people were concerned about them, and they mostly came from welfare rights organizations or similar rights organizations, with good training, that is how we accomplished it.

I am well aware, and as I congratulated this lady on her testimony, that some of the things she said are vital to this program.

But I think the one thing that has to be done if you are going to use the outside welfare organizations is that you are going to have to set up good training programs so that they understand why they are out there, why they are knocking on doors, and what they have to tell the people.

It just cannot be left to them to just go out and say there is a good program for your children. It just doesn't work.

Mr. MAGUIRE. Ms. Clarke, I wonder after 3 years of experience in your outreach efforts if you could tell us a little bit more about what you find does and doesn't work? Have you tried some strategies that really didn't work out? Do you find that you have to go back two or three times for personal visits as Mr. Perlman suggests sometimes is necessary, or can you do it all on the first visit? What is your experience?

Ms. CLARKE. At Tri-City we see outreach as an ongoing part of health care. We sometimes do have to go back two or three times, but in these places we see that perhaps the family have other problems that distracts the energy from coming into the clinic. We try to alleviate these other problems. A mother might have problems with housing or with heating in the winter.

So we have an aid and information center. We refer them to our aid and information center and try to help them with these pressing problems so after these problems are taken care of, the people come in. Even sometimes it might be 1 year later, but we feel that our contact with the person enlightens the person. The person is much more knowledgeable after the meeting than perhaps when the other problems have been taken care of.

She knows what she needs to do for her children. She knows where she should go and she in turn goes. We don't see it as a one-stop situation that if we did not solve the problem and the mother didn't come in right away, we don't call that failure. We see in outreach that something happens when we knock on the door. The person knows that we are in the community. The person knows that we are there to help. That is important.

Mr. MAGUIRE. Mr. Perlman, your success is also based on the outreach as well as working with providers, is it not?

Mr. PERLMAN. Yes, sir. I think a great deal of it has to do with the cooperation we finally got from the county boards of assistance workers and our own outreach program in Allegheny County.

Mr. MAGUIRE. And you hired persons from the Welfare Rights organization to do your outreach?

Mr. PERLMAN. Yes, sir.

Mr. MAGUIRE. How many did you have across the State doing that?

Mr. PERLMAN. I think we had about 30 people working in our outreach program in Allegheny County.

Mr. MAGUIRE. But you didn't have them in the other 61 counties?

Mr. PERLMAN. No, the States did not provide funds for that, but we worked very closely with the county boards in those areas. I think you have a different problem in the urban areas of the cities than in the more rural areas. You have different problems there of not being able to find providers, but you don't have the same problem with outreach.

Mr. MAGUIRE. Pittsburgh isn't the only city in Pennsylvania. What did you do with Philadelphia?

Mr. PERLMAN. Philadelphia was handled by a different organization. The State was divided and five counties were given to another organization.

Mr. MAGUIRE. Thank you, Mr. Chairman.

Mr. WAXMAN. I want to thank you very much. It has been a very helpful discussion and good testimony.

We would like to now call a panel on data: William Hickman, Director, Division of Analysis and Evaluation, Medicaid Bureau, Health Care Financing Administration; James McKittrick, program director, EPSDT, Department of Public Welfare, State of Pennsylvania, and Mr. Michael Gelder, president, Michael A. Gelder & Associates, Inc.

We are pleased to have you with us and welcome you to the committee.

Mr. Hickman, why don't we hear from you first?

STATEMENTS OF WILLIAM HICKMAN, DIRECTOR, DIVISION OF ANALYSIS AND EVALUATION, MEDICAID BUREAU, HEALTH CARE FINANCING ADMINISTRATION, PUBLIC HEALTH SERVICE, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE; JAMES MCKITTRICK, PROGRAM DIRECTOR, EPSDT, OFFICE OF MEDICAL ASSISTANCE, PENNSYLVANIA DEPARTMENT OF PUBLIC WELFARE; AND MICHAEL GELDER, PRESIDENT, MICHAEL A. GELDER & ASSOCIATES, INC.

Mr. HICKMAN. Thank you, Mr. Chairman.

My name is William Hickman, Director of Analysis and Evaluation in the Medicaid Bureau, Health Care Financing Administration, HEW.

Since the Department has testified on this proposed legislation, I have not been requested to prepare a written statement at this time. But I would be very happy to answer any questions on the data area.

Mr. WAXMAN. Thank you. We will hear from the other two and then we will have questions of all three of you.

Mr. McKittrick?

STATEMENT OF JAMES MCKITTRICK

Mr. MCKITTRICK. Good afternoon. I want to thank you for inviting me today.

My name is James McKittrick. My home is Harrisburg, Pa. At the present time I am employed by the Pennsylvania Department of Public Welfare, office of medical assistance as director of the EPSDT program.

I have been involved with this program for more than 5 years. During that time, from January 1974 when the first child received services in Pennsylvania under this program, over 700,000 children have been screened. At the current time an average of 15,000 children a month receive this service under the medical assistance program. Our State population of AFDC, SSI, medically needy, general assistance, foster care, and children in families with one unemployed parent who are eligible for the program is approximately 510,000.

There are numerous questions to be raised regarding this proposed legislation. Among them are:

First, What are the specific goals of this legislation? How will it be monitored? How successful is preventive care in reducing incidence of childhood disease? How can this be measured? For every dollar spent now in this program, what savings can be predicted in terms of future costs resulting from untreated problems?

Second, how will this program provide health care in areas where there are provider shortages for all classes of people? By the same token, how will this program improve upon the numerous working programs that exist in the large urban areas and now actively compete for the same children?

These are the same questions that the EPSDT program raised 12 years ago. Thus far, none of them have been answered. I urge you to require a real evaluation component to be built into this program.

As I am sure you realize, nothing is more controversial or fraught with conflicting opinion than a mass screening program dealing with health care for children. A social service program, like any other worthwhile Government program, deserves to have its case made for it by hard examination of the facts. Bringing out a new improved program which fails to deal with the problems of its predecessor is really a shell game. Specifically, what in the program that is proposed is different from EPSDT?

Actually, there is not a whole lot when you consider the design. However, there is one important area in the administration bill, H.R. 4053, that I feel is very worthwhile. That something is the provision for monitoring children already under care.

The provision allows for considering a child to have met the circumstances and intent of the program if the State agency has a written agreement with a provider to manage that health care. This, of course, will now answer every problem. Just how such agreements will be worded and enacted is left to be worked out.

The question raised in this is how do you get providers to sign an agreement? Is it like a retainer used in the legal profession? How much responsibility do they assume? How do you get a tie-in between the most common types of providers, that is, family physicians, pediatricians, general practitioners, well-child clinics, and the most common specialists needed in this program: Dentists, eye care specialists, allergists, and developmental specialists without the possibility of fee splitting, kickbacks, and other limits of freedom of choice?

I don't know how to answer those problems, but I think they are preferable to a horrendous tracking system where no agreement exists.

These problems are:

First, the State agency and not the provider and the parent becomes responsible for the child.

Second, the documentation of a whole generation of children's health care is expensive in terms of dollars—\$10 to \$15 a child is our best estimate based on what now goes on in EPSDT in a similar circumstance—and in the potential invasion of privacy.

Third, the mechanics of documentation are not simple. Right now we have not resolved this problem in EPSDT. In Pennsylvania we have a system that is fully automated for the screening assessment and then breaks down on the following issues:

How do you identify the screened child as he travels from provider to provider? You can't put a sticker on his doorjamb like you do with your car at an oil change.

How do you identify screening-induced treatments from self-referrals; or initiated treatments? In other words, he got screened

this week and they didn't find anything wrong and he got a cold and went back to the provider and got treatment for that. How do you know which treatment was which?

How do you avoid lumping together statistics that take into account self-limiting referrals for example, colds and stomach flu along with serious problems such as anemia or lack of immunization? Such a system as now exists in EPSDT gives all conditions the same priority resulting in a lot of time and confusion spent in documenting many items which are of no consequence.

How do you avoid the systematic trap of making health care a linear process screening to diagnosis to treatment as if they were all stops along a railroad track? In most cases health care is dynamic. There is interaction between the provider and the patient. It is not easily broken down. As a program official, it is very hard for me to determine where screening ends and diagnosis begins, and where treatment begins and ends. I don't think this should be our concern.

In summary, therefore, in all your discussion and consideration of this bill I hope you will retain that part of the administration's CHAP provision which allows for a sensible approach to arriving at a worthwhile goal—access to medical care for children through provider agreements rather than forcing agencies into the confusing world of health care tracking.

As a postscript, I also endorse the concept of the higher Federal match in this bill. I think the initials in this bill, CHAP, are much more preferable to the EPSDT. I think CHAP is a big improvement just in the name.

Mr. WAXMAN. Thank you.

Mr. Gelder?

STATEMENT OF MICHAEL A. GELDER

Mr. GELDER. Thank you.

Mr. Chairman and members of the subcommittee, I am Michael Gelder, president of Michael A. Gelder & Associates, as the witness list indicates, and also the EPSDT project director for Community Health Foundation, Evanston, Ill.

Through both my company and Community Health Foundation, I have devoted the last 5 years to helping HEW, States, and local health and welfare departments and community organizations improve their EPSDT program by providing consultation and technical assistance.

Through contracts with HEW, I have provided and managed technical assistance to 13 States for their EPSDT program, covering the entire realm of EPSDT functions: client identification, Outreach, provider recruitment, screening package, rescreening schedule, interagency coordination, and case management. These States ranged from Hawaii to Connecticut and Washington to Louisiana in terms of location and from California to North Dakota in terms of size and complexity.

For the last 2 years I have worked intensively on interagency coordination and case management. This included helping California define its case management needs and designing and implementing a case management system for a large urban county. CHF

is currently providing technical assistance to New Jersey for its case management needs.

I appreciate this invitation to share with the subcommittee some of the myriad of lessons we have learned from these experiences over the last 5 years. I understand that the topic this panel is addressing is data systems and case management, and I will confine my oral remarks to these areas.

The written testimony also addresses general issues of EPSDT and CHAP and I will be happy to address other areas as well during questions. It covers the lack of and need for clearly defined purposes and objectives, EPSDT's need for greater visibility and accountability, the lack of a constituency for EPSDT and need for expanded eligibility, barriers to agency coordination, the constraints of financial participation, and the need for financial incentives, and, finally, case management.

My remarks on case management begin on page 7 of the written testimony. The function of case management is to assure the timely delivery of all appropriate services to eligible families. Assuring the delivery of services—linking children with the health care system—is the crux of the entire EPSDT program. This responsibility is the primary characteristic which distinguishes EPSDT from the general medicaid program, which is primarily concerned with claims processing and payment.

It requires that staff monitor the status of each individual eligible for the program, assure that services are available, and that clients be encouraged to take advantage of the appropriate services.

The periodic nature of EPSDT service means that the process be repeated continually while children are eligible for the program.

The administrative steps necessary to accomplish this—assuring the timely delivery of services, linking each child with the appropriate health care resource, monitoring their progress through the maze of services—is case management.

Although case management may be viewed as one component of an EPSDT program, it is the component that links the other components together. It relates the identification of eligibles to informing and outreach activities; it relates outreach to referral to health care providers for screening, diagnosis and treatment; and it relates the need for health and medical care to the identification and delivery of other support services that families may need.

Case management, then, is necessary to link the many disparate elements of the health and welfare systems. It must integrate welfare eligibility and social service information with health service delivery data and compare this information against a standard schedule of screening times and components.

To fully understand the current case management issue, it is important to realize that recognition of its value is a relatively recent development. During the first years of the program, little attention was paid to the development of case management. HEW and State administrators first concentrated on the screening packages, rescreening schedules, training and development of health resources, and administrative mechanisms for paying claims.

HEW and local program administrators are now directing increasing attention to organizing and coordinating all of the services

and agencies involved in EPSDT. They now recognize case management as the means by which that can be accomplished.

Nearly every State program and hundreds of county programs are struggling with the complex tasks associated with case management development. Many have, or are developing, basic systems to satisfy minimum penalty and reporting requirements.

Nevertheless, the technology and skills are available. A number of HEW contractors have developed conceptual designs and more specific general systems designs, and a few States and counties have installed rudimentary case management systems.

The complexity of the systems varies, depending on the nature of the program in the State—that is, all organized health department screening providers or all independent private practicing physicians—and the personnel available to act on the information generated.

The primary obstacles to case management development, rather than the lack of capability, are attitude and cost. I have found States to resist because: One, they are not certain that case management is what HEW really wants; two, it defies the general Medicaid laissez-faire attitude of paying bills only when submitted; and three, the case management concept smacks of State interference with the practice of medicine. I am sure there is an element of truth to each of these, but they are also excuses to some extent.

The cost of such systems is the more tangible reason and easiest to address. Case management is not cheap. Although the data processing systems themselves are inexpensive, running \$2 per child screened, case management systems require the staff to intervene when necessary and provide the necessary assistance. This can equal the cost of the screening itself.

A good case management system can allow staff to work on an exception basis, thus eliminating a lot of extra paperwork for those who need no help. But for the ones who do, the 10 to 40 percent who now normally fall out of the program completely, the task is labor intensive and will increase State costs. The outreach, referral, and followup activities directed by case management can run as much as the assessment itself. The best State programs spend approximately \$20 to \$30 on both screening and case management.

This is why the Federal financial participation incentive is critical for case management. If Congress is serious about CHAP and recognizes the value of case management, then the incentive must be high enough to offset the increased program expenses of installing, operating, and staffing such systems and the incentive should be applied directly to a measure of those enrolled and under case management.

Another way of accomplishing that is to offer the higher match only for those who are being served under CHAP. If the match is high enough, the case management system will quickly evolve to document and claim the higher match for the higher number of children served.

I appreciate the opportunity to appear here today, and will be happy to supply any additional information and assistance that would be helpful to the committee.

[Testimony resumes on p. 285.]

[Mr. Gelder's prepared statement follows:]

STATEMENT OF MICHAEL A. GELDER, PRESIDENT, MICHAEL A. GELDER & ASSOCIATES

Mr. Chairman, Members of the Subcommittee:

I am Michael Gelder, President of Michael A. Gelder and Associates, as the witness list indicates, and also the EPSDT Project Director for Community Health Foundation, Evanston, Illinois. Through both my company and Community Health Foundation I have devoted the last five years to helping HEW, states, and local health and welfare departments and community organizations improve their EPSDT program by providing consultation and technical assistance. Through contracts with HEW, I have provided and managed technical assistance to 13 states for their EPSDT program, covering the entire realm of EPSDT functions: client identification, outreach, provider recruitment, screening package, rescreening schedule, interagency coordination, and case management. These states ranged from Hawaii to Connecticut and Washington to Louisiana in terms of location and from California to North Dakota in terms of size and complexity.

For the last two years, I have worked intensively on interagency coordination and case management. This included helping California define its case management needs and designing and implementing a case management system for a large urban county. CHF is currently providing technical assistance to New Jersey for its case management needs.

I appreciate this invitation to share with the subcommittee some of the myriad of lessons we have learned from these experiences over the last five years. I understand that the topic this panel is addressing is data systems and case management, and I will confine

my oral remarks to these areas. The written testimony also addresses general issues of EPSDT and CHAP and I will be happy to address other areas as well during questions.

I am also pleased for this opportunity to influence the shape of the new legislation so that some of the problems which have plagued EPSDT (and kept it one of the best kept secrets in the country) can be eliminated. Any new legislation must insure strong, forceful federal leadership to overcome the states' tendency to hold back on costs, define programs narrowly, and pass responsibility up and down and across organization charts until no one knows or cares who is doing what. I must emphasize that states are not the enemy. Within each state I have worked, including some that are doing very poorly, there are staff strongly committed and enthused about EPSDT. These people need strong federal legislation and regulation as the basis for their superiors to approve their requests for the funds and support needed to implement EPSDT.

But HEW has never answered the basic questions raised by EPSDT which have strong ramifications for state administration. Is it primarily a health or welfare program? Is it a special and limited adjunct to Medicaid intended to identify potentially handicapping conditions and assure referral for treatment, or is it a broader program designed to place all children under the on-going care of a comprehensive medical provider? Is it a preventive health program or an early identification program? Is it intended to encourage community organization participation and the use of paraprofessionals or is it a referral program to private practitioners? Is it intended to emphasize health education, promote positive nutrition habits,

encourage links with schools and other community resources, or is it a program to refer Medicaid beneficiaries under 21 to the same type of health providers middle class families frequent?

The tendency has been to answer "yes" to each. Few choices or hard decisions have been made, and this has been the cause of much confusion. The answers to some of these questions, fortunately or unfortunately, require mutually exclusive administration responses. Programs administered by health departments invariably have different focuses and community images and responses than those administered by welfare agencies. Community participation and use of paraprofessionals are lessened when EPSDT focuses on referring children to private practitioners. Similarly, less emphasis is usually placed on health education, counseling and nutrition in states where EPSDT primarily refers children to private providers. Interagency coordination also diminishes with increased reliance on private providers.

Thus EPSDT or CHAP cannot be all things to all people or special interest groups. If the new legislation clearly defines CHAP's purpose and intent in the context of these types of questions, then one significant obstacle for EPSDT will be overcome.

The second major problem plaguing EPSDT has been its insulation. HEW and states have made crucial decisions about the program, funding, priority, policy, etc., insulated from public opinion. HEW, in the past, has "chosen" to allow the program to muddle along without adequate staff, contract funds, support from Medicaid and other HEW components. Likewise, states have "decided" that their programs would serve only 10 per cent of the eligibles. They have decided

not to raise provider fees, not to add staff, not to effectively encourage clients to make use of EPSDT, not to contract with community organizations, not to install tracking systems: in effect, not to implement the program. But all of these decisions have been administrative, executive, management ones, sheltered from community opinion.

If the new legislation builds in oversight, Congressional at the federal level as well as "community" at the state and local levels, another significant obstacle will be removed. I endorse the concept of establishing child health advisory committees which would hold public hearings on EPSDT state plans and be responsible for annual review and evaluation of the program. Charging state Health Coordinating Councils and State Health Planning and Development Agencies to review CHAP performance is another possible approach.

The third problem with EPSDT has been lack of constituency. This is primarily an issue of eligibility. No one lobbies for EPSDT. This is, in part, due to its overall invisibility. Few are served by it long enough for it to matter. With the average eligibility turnover rate of 3 to 5 years, few children are eligible for more than two or three assessments after infancy, given the states' infrequent periodicity schedules. Worse, the categorical Medicaid eligibility requirements result in few "groups" of children all being eligible. Thus, Head Start programs, 4-C programs, day care councils, Title I schools or other organized settings for poor children with parent participation do not actively advocate for EPSDT because only fractions of their enrolled children are eligible. Large states

are increasingly reluctant to engage in any effort that could result in more children becoming Medicaid beneficiaries and will not undertake this voluntarily. If CHAP could mandate eligibility for all children enrolled in these types of settings, much would be done to alleviate one of EPSDT's most invidious problems. I fear that if CHAP performance standards are based on a percentage of total Medicaid enrollees, states will be more reluctant to add more children to the Medicaid roles.

The fourth problem, interagency coordination, is closely related to the third problem. I have recently completed a project for HEW analyzing the potential areas of coordination with EPSDT for over 60 other federal HEW programs. Some have very little value for EPSDT but some are crucial for case finding, service delivery, and case management. Yet, with the exception of the SSI disabled children's program, Child-Find under P.L. 94-142, Title V programs, and a few others, there is no legislative mandate for coordination. In other cases, Title XX Social Services, for example, legislation precludes federal efforts to require coordination with EPSDT, resulting in duplication of staff efforts and data systems in some states and counties, and total neglect in others. Even where the legislative mandate exists, such as in Title V programs, there is no federal pressure to comply and some federal regional offices actually advise their projects not to participate with EPSDT.

CHAP could significantly aid attempts to develop a coordinated child health strategy by mandating the development of common service delivery packages, reporting requirements, and clarifying and

expanding Medicaid's first dollar responsibility. These are clear needs which CHAP must satisfy.

The fifth problem is that of Federal Financial Participation (FFP). The penalty on AFDC funds has confused the local administration of EPSDT. The lack of any substantive financial incentive left HEW without any carrot to lead states to better performance.

Some states are utilizing the 75 per cent FFP available for certain administrative costs for EPSDT outreach, referral, and follow-up. This is the only incentive HEW now offers. Nevertheless, it is limited to skilled medical professionals and their support staff who are employees of public agencies. States are not entitled to the higher match rate if they prefer to contract with community organizations for these functions. Although such arrangements have been very successful, federal law and regulations do not allow the higher administrative match to be used as an incentive for this purpose.

Medicaid is the green blob gone berserk in most state budgets. It is malignantly devouring everything in its way, doubling every five to six years. States are naturally directing their energies to limiting that increase. Claims payment and eligibility are the subjects of that concern and MMIS is looked at for salvation. But MMIS does not yet generally have an EPSDT component. Ironically, EPSDT is neglected because of its relative low cost. As a low cost budget component, it gets very little attention. But the only thing certain in most states is no budget increases.

In this environment, to attract attention, the fiscal incentive offered must be substantial and specific. If incentive, rather

than penalty, is the preferred approach, then it should be clearly related to the desired performance to be effective. I believe that the higher match rate for services for children up to date with their CHAP assessment schedule, will serve as a greater and more specific incentive for states to bring children into the program and assure that they receive all of the services to which they are entitled. Since that is the objective of CHAP, I find that to be a better use for the incentive. And because of the sorry state of most Medicaid budgets, a match of 90 per cent is needed before states will be willing to increase costs for the program.

The FFP issue raises the sixth and last, but certainly not least problem of data collection and case management. Case management is an element of a number of previous problems, but it can best be understood in the context of the overall program.

The function of case management is to assure the timely delivery of all appropriate services to eligible families. Assuring the delivery of services--linking children with the health care system--is the crux of the entire EPSDT program. This responsibility is the primary characteristic which distinguishes EPSDT from the general Medicaid program, which is primarily concerned with claims processing and payment. It requires that staff monitor the status of each individual eligible for the program, assure that services are available, and that clients be encouraged to take advantage of the appropriate services. The periodic nature of EPSDT services means that the process be repeated continually while children are eligible

for the program.

The administrative steps necessary to accomplish this-- assuring the timely delivery of services, linking each child with the appropriate health care resource, monitoring their progress through the maze of services--is case management.

Although case management may be viewed as one component of an EPSDT program, it is the component that links the other components together. It relates the identification of eligibles to informing and outreach activities; it relates outreach to referral to health care providers for screening, diagnosis and treatment; and it relates the need for health and medical care to the identification and delivery of other support services that families may need.

Case management, then, is necessary to link the many disparate elements of the health and welfare systems. It must integrate welfare eligibility and social service information with health service delivery data and compare this information against a standard schedule of screening times and components.

To fully understand the current case management issue, it is important to realize that recognition of its value is a relatively recent development. During the first years of the program, little attention was paid to the development of case management. HEW and state administrators first concentrated on the screening packages, rescreening schedules, training and development of health resources and administrative mechanisms for paying claims.

HEW and local program administrators are now directing in-

creasing attention to organizing and coordinating all of the services and agencies involved in EPSDT. They now recognize case management as the means by which that can be accomplished. Nearly every state program and hundreds of county programs are struggling with the complex tasks associated with case management development. Many have, or are developing, basic systems to satisfy minimum penalty and reporting requirements.

Nevertheless, the technology and skills are available. A number of HEW contractors have developed conceptual designs and more specific general systems designs, and a few states and counties have installed rudimentary case management systems. The complexity of the systems varies, depending on the nature of the program in the state (i.e. all organized health department screening providers or all independent private practicing physicians) and the personnel available to act on the information generated.

The primary obstacles to case management development, rather than the lack of capability, are attitude and cost. I have found states to resist because: (1) they are not certain that case management is what HEW really wants; (2) it defies the general Medicaid laissez-faire attitude of paying bills only when submitted; and (3) the case management concept smacks of state interference with the practice of medicine. I am sure there is an element of truth to each of these, but they are also excuses.

The cost of such systems is the more tangible reason and easiest to address. Case management is not cheap. Although the data processing systems themselves are inexpensive, running \$2.00

per child screened, case management systems require the staff to intervene when necessary and provide the necessary assistance. This can equal the cost of the screening itself. A good case management system can allow staff to work on an exception basis, thus eliminating a lot of extra paperwork for those who need no help. But for the ones who do, the 10 to 40 per cent who now normally fall out of the program completely, the task is labor intensive and will increase state costs. The outreach, referral and follow-up activities directed by case management can run as much as the assessment itself. The best state programs spend approximately \$20 to \$30 on both screening and case management.

This is why the FFP incentive is critical for case management. If Congress is serious about CHAP and recognizes the value of case management, then the incentive must be high enough to offset the increased program expenses of installing, operating and staffing such systems and the incentive should be applied directly to a measure of those enrolled and under case management. Another way of accomplishing this is to offer the higher match only for those who are being served under CHAP. If the match is high enough, the case management system will quickly evolve to document and claim the higher match for the higher number of children served.

I appreciate the opportunity to appear here today, and will be happy to supply any additional information and assistance that would be helpful to the committee.

Mr. WAXMAN. Thank you very much.

Mr. Maguire, why don't you lead off with questions?

Mr. MAGUIRE. Mr. McKittrick, first of all, 700,000 children have been screened. What percent of those are eligible in the State of Pennsylvania?

Mr. MCKITTRICK. We figure roughly 80 percent of the eligible population has made a decision on screening, either they have been screened or they have signed a document saying no.

That 700,000 we would say is about 65 percent of the eligibles that have actually taken advantage of the program and gotten screened.

Mr. MAGUIRE. So 15 percent said no?

Mr. MCKITTRICK. And the other 20 percent somehow or the other fall through the cracks.

Mr. MAGUIRE. Mr. McKittrick, I notice that as a representative of a State office that has been concerned with this, you are not very anxious to do case management.

Mr. MCKITTRICK. It is not that we are not anxious to do case management. I think we would like to take the option as presented in the administration bill to contract that out to providers, that is, physicians, and hire clinics to enter into agreements where they will monitor the child's health care.

As an agency we are doing some of that now. It is not a matter of fact that we don't have the equipment or we couldn't get the personnel or I could beef up my staff to do it. That is always an option that I wouldn't mind.

However, it is very expensive and it is very confusing. A lot of times it ends up being meaningless. We get a lot of statistics that don't mean a whole lot. We get a lot of information that we really don't need. It really doesn't have any real impact on that child's health care.

Mr. MAGUIRE. Surely we ought to be able to design a system that would give us the information we want and that would not give us the information that we don't need.

Mr. MCKITTRICK. That is possible, but I don't know how. In other words, I have been involved in this for 5 years and I am saying I really don't know how. That is not an admission I am proud of, but that is something I am bringing up. It is very difficult to do that. It has not been done before.

So you are really into a new area.

Mr. MAGUIRE. We had some providers here last week who indicated a great reluctance to take on tracking, case management responsibilities. They thought the State agencies were the ones best prepared and able to do that work. So we have reluctant dragons on both sides it appears.

Mr. MCKITTRICK. I don't know what the reluctance is based on. As you heard before from Mr. Perlman, we had reluctance from the medical community to participate in this program at all when you talked to organized representatives. We sought them out individually and talked to them and talked them into it.

I think we could take the same approach to this plus a financial incentive for them to do so.

Mr. MAGUIRE. Mr. Gelder, can you shed any light on this? You have said it is a labor-intensive matter. Does that mean in your

judgment providers can't do it and State agencies should do it, or if providers do it, it is just signing a written document to get the job done? How do you provide the labor-intensive part?

Mr. GELDER. I am not advocating duplicating at the State or county level duties which could be expected to be performed in a doctor's office or most clinics. The problem I have found is that the large number of referrals are out of the doctor's offices. The referrals that are found, particularly in EPSDT assessments, are for vision, hearing, dental and perhaps development problems, all of which are referred out of the typical doctor's office.

So even doctors who are capable of managing the client's progress for medical services are not capable of doing the same sort of thing for the child referred to a dentist, optometrist, or ophthalmologist. Some kind of tracking system is still necessary because these are not functions physician's offices are prepared for.

Mr. MAGUIRE. So how does that get done?

Mr. GELDER. There are a variety of options. I don't want to preclude the option of those health facilities, the organized community health centers, and other clinic arrangements where the variety of health services are available under one roof and where their recordkeeping is capable of following children and assuring they are receiving all the help that is identified as needed. But these clinics are not available to all children we are trying to reach.

The alternative to contracting with clinics and those community organizations that can provide all the care is to place the responsibility on the public agency, either the health or welfare department, that can intervene when necessary.

It is not a question of pushing the child, but to follow his or her progress and then take the appropriate action if the services are not being received.

So the answer I guess is that the staff would be employees of the public agencies or special community organizations that would be under contract to the public agencies responsible for the program, and that they would do the staff work.

Mr. MAGUIRE. Mr. McKittrick says he doesn't think that you can easily develop the right kind of data for following somebody at a distance, if you will. Is that a fair statement?

Mr. MCKITTRICK. Yes. It is not only the right kind of data, but when and where you plug the data in.

Mr. MAGUIRE. What is your response to that, and maybe we can ask Mr. Hickman also?

Mr. GELDER. I think that is certainly true.

One of the big problems with developing a case management system for EPSDT so far has been the lack of a really clear definition of what the program is and what it is supposed to accomplish.

Short of being the medicaid program for children, we do run into problems of knowing which medical services are EPSDT-related and which are not. But if that barrier were removed and if EPSDT or CHAP became the medical services under medicaid for all children, all medical services would be a part of the same data or case management system.

So we would not have to worry about whether it is EPSDT-related or not. It would all be part of the health services being made available to children and thus capable of being tracked and

followed with the appropriate intervention by staff, community workers, or public agency employees who would take the appropriate action to assist the family if they are interested.

Mr. MAGUIRE. Mr. Hickman, do you have anything to suggest on what would be the appropriate case management model here?

Mr. HICKMAN. I think the big problem in data is finding out after the child was scheduled for screening if he received the screening and after he went through screening, whether the problems uncovered at that point were taken care of in treatment.

I think this is the heart of the data matter. The other two gentlemen are correct that the means are all difficult and have some problems. But there are several ways of doing it.

One is to have a staff of case management workers who actually make telephone calls to provider offices. This model is being used in some places. For example, I think its been used to some extent in Pennsylvania.

Another way is to try to link up information that comes back on the claims form. When the provider who did the screening sends in a claim form to get his fee for the screening, usually all the data is there that indicates the problems found in screening.

When a provider sends in a claim form to get paid for treatment, this becomes a little more difficult situation because you are not sure that it is treatment related to the screening that preceded it.

But within the claims processing systems there are ways of linking up problem codes from the screening form with diagnosis codes from the treatment form and getting a pretty close approximation that the treatment actually was rendered because of that treatment form.

So the basic two systems are through claims or through case-workers making calls to doctor's offices.

Mr. MAGUIRE. In either case that has to be a State function, then?

Mr. HICKMAN. That is a State function. I think there are two data issues that may need to be separated when we discuss all these bills. There is one data issue about how a State keeps track of whether or not the children are getting the services they are supposed to get.

There is another data issue involved with what data has to be available to the Federal Government to run any incentive or penalty system. They are related, but they are not exactly the same issue.

Whether we are operating EPSDT and don't have any CHAP legislation or whether we take any of the CHAP bills, one has to deal with this question of the States tracking children somehow.

The administration's bill contains a continuing care provider option and as Mr. McKittrick mentioned, the onus will be on providers when they sign continuing care agreements.

But even there, for Federal monitoring purposes we would want to recheck to see that some kind of activity was going on with that child who was signed up with a provider.

Mr. GELDER. I have one other comment in answer to your question, Mr. Maguire. The problems of case management are very much State specific and program specific. Capturing the data in States where the assessment services are primarily delivered

through health departments is a much simpler task than trying to organize a case management system in States where they are delivered primarily through independent private practicing physicians. The control that the State has and the ability to monitor and follow children's progress is diminished considerably when it is diluted through private physicians.

Mr. MAGUIRE. Have any of the States that you have worked in been successful, like Pennsylvania, in percentage of children reached and the overall followthrough of the program?

Mr. GELDER. No. I think Pennsylvania serves as a model and goal for all the States that I have worked in.

Mr. HICKMAN. I think that is true across the country in terms of screens. We did a study of nine States in rates of getting treatment. Pennsylvania was highest in that category, too.

Mr. MAGUIRE. I might just say in concluding, Mr. Chairman, I think not all of the panelists are aware, on this panel or on other panels, that the bill that you and I have introduced also requires the people to sign to participate in the program.

The administration bill is not unique except in that it provides that written agreement only for a portion of the people who are participating instead of all of them who are participating.

I think that is accurate, as a way of summarizing the contrast between the two bills.

So whatever you said about the administration bill, that was nice, note that it applies with even greater force to the Maguire-Waxman bill.

Thank you.

Mr. WAXMAN. Thank you, Mr. Maguire.

Mr. Leland?

Let me thank the panel. You have been very helpful to us. We appreciate your taking the time to present invaluable testimony.

We would like to now call a panel on nutrition: Buford Nichols, M.D., department of pediatrics, Baylor Medical School of Houston, Tex., and George Owen, M.D., University of Michigan, representing the National Nutrition Consortium.

Mr. LELAND. Mr. Chairman, I would like to introduce the panelists who are here, in particular Dr. Buford Nichols who I have known for at least 12 years. He has been very involved not only in the area of nutrition, but as well has served as a volunteer in a very serious program that was begun in the fifth ward of Houston, Tex., where I grew up. He helped to establish a free health clinic where we developed an outreach program and did many of the things that we are trying to accomplish, at least we attempted voluntarily to do many of the things we are trying to do here, through CHAP.

I commend him to this Congress.

I want to welcome Dr. Owen as well, who has cooperated with my staff and has come far to participate in this hearing.

Mr. WAXMAN. Thank you very much. I want to thank you, too.

STATEMENTS OF BUFORD NICHOLS, M.D., PROFESSOR, DEPARTMENT OF PEDIATRICS, BAYLOR COLLEGE OF MEDICINE; AND GEORGE M. OWEN, M.D., ANN ARBOR, MICH.

Dr. NICHOLS. Mr. Chairman, I am Buford Nichols. I am a professor of pediatrics and physiology at Baylor College of Medicine. I am also head of the section of nutrition and gastroenterology, and am the scientific director of the Children's Nutrition Laboratory of the Human Nutrition Center, SEA, USDA.

My association with Mr. Leland goes back to a free clinic at Houston, Tex. I will never forget the night some of our student doctors called me and said, "Black Panthers were standing in front of the clinic and threatening to burn it down and what should they do?"

I said, go out the back door.

We learned a lot about communicating with the community since then, haven't we?

Mr. LELAND. Yes; we have.

Dr. NICHOLS. I want to address the act that Mr. Leland has introduced entitled "Maternal and Childhood Disorders and Information Act of 1979." The act is one which tends to enhance the existing programs and addresses the problems of identification of those individuals who are likely to benefit from nutritional intervention and referral of these subjects to existing programs.

In addition, there is a strong request that the Departments of Agriculture and HEW coordinate their activities in the field of childhood nutrition research.

My written testimony relates to my view of how this coordinated effort should be launched as a national program in childhood nutrition research.

The third major feature of this legislation is that it gives a bold new initiative of approach to public nutrition information using the mass media.

I have had personal opportunity to see the strong devotion of the worker in the field of human nutrition and health care delivery who has tried to bring to the problems of malnutrition and poverty a devoted attempt to alter the course of events.

I have seen hungry children in south Texas, and I still take care of hungry children in the fifth ward. What is the basic problem? We did a brief analysis in 1970 concerning the seven counties in south Texas which are supposed to have the highest poverty index in the United States. We took the estimated budget deficit and calculated for individual families in those seven counties the amount of income necessary to bring them out of the poverty level.

At the same time we analyzed the total Federal dollars going into welfare programs and the food stamp programs, and we were very surprised to find that in those seven counties the income deficit necessary to bring these people out at the poverty level was exceeded by 20 percent.

I have been there. I had seen the poverty and known that the programs had existed, but were not reaching the target population. We have heard discussion today about the problems of implementing EPSDT and the problems of implementing a revised CHAP program.

But I would say the scope of the problem is wider than the CHAP program. The problem is related to the fact that there are over 100 agencies involved in child health and the children are following through the 99 cracks between the programs.

What we need is not more logic but more understanding. We need to turn our systems around to the tracking of individual children not only within the CHAP program but within the total programs.

Let me give you an example. Right now the WICK program has grown to the point where the funding is twice that of the estimated budget of the CHAP program. This particular program was designed to be a nutrition component established in the health care system. The reason we can't implement it in Houston, in the fifth ward, is that the health care system is inadequate.

We need to remedy the problems of health care delivery and bring it up so that it balances the feeding programs.

Mr. Leland's bill addresses the problem of identifying these children and bringing them to the point of coordinated participation in these existing programs that by and large do provide adequate resources if, and at the present time the big "if" is this, if the family is able to cope with the system.

What we are essentially finding is that coping with the system determines the child's outcome.

Those are my comments.

[Testimony resumes on p. 308.]

[Dr. Nichols' prepared statement and attachments follow:]

STATEMENT OF BUFORD L. NICHOLS, M.D., PROFESSOR, DEPARTMENT OF PEDIATRICS,
BAYLOR COLLEGE OF MEDICINE

THE ROLE OF THE RDAS IN CHILD HEALTH, PROTECTION
AND CARE

I. INTRODUCTION

The increasing complexity of social structures such as commerce, agriculture and health have placed an increasing demand on objective data as a basis for the management of our national resources. The need for such objective data in the field of human nutrition becomes increasingly important in the next half century as the population burden approaches the limit of existing resources and technical capacities. As an example, an overestimate of animal protein requirements can lead to inefficient use of our cereal grains in livestock feed when the international requirements for cereal grains are already in excess of available supplies. Our overwhelming contribution to the world's exportable food supply places an unprecedented responsibility on the United States to utilize this renewable resource most efficiently and to maximize its availability to the world. It is evident that the objective estimate of human nutritional requirements is a necessary first step to immediate and long-term agricultural planning in the complex society in which we live.

Historically and by necessity, social planning in the United States has relied on the estimate of nutrient allowances by the National Academy of Sciences. This report, the RDA, now in its eighth edition, has made a substantial contribution to the definition of "acceptable daily nutrient intakes". It is used for planning and procuring food supplies for population groups such as the military, the interpretation of food consumption records, and in the development of policy for health and welfare programs. It plays a role in the design of research and nutrition surveillance programs and in nutrition education. As a working document, the RDA provides a valuable resource to those responsible for social policy development.

In the application of nutrition knowledge to child health, the RDAs are used every day by the dietitians, nurses and physicians who work to promote health and to cure disease. Attached, in an appendix to this testimony, are a series of statements by these health workers outlining how they utilize the standards for nutrient intake provided by the RDA. The document, now entering the ninth edition, serves as a rela-

tive and at times absolute reference against which all dietary manipulation is compared.

The RDA have a proven value in their present form, however, it is necessary to evaluate the precision and adequacy of these recommendations. More specifically, how objective are these recommendations for children and infants? This is a question which must be answered individually for each of some 30 nutrients of recognized requirement and an additional eight trace minerals of unknown requirement. The RDA does not discuss essential amino acids.

A point by point analysis of the existing RDA recommendations is summarized in Table 1. Several generalizations are possible from such an analysis. No discussion was possible concerning the infant's recommendation of nine nutrients. The allowances of seventeen nutrients are based upon the average intakes of breast fed infants. Weight gain and growth were the major criteria for recommended energy and protein intakes. The precision of the estimate of allowances was non-existent for 18 nutrients; poor for 8; fair for 3 and good for one. From present knowledge it is impossible to assess the adequacy for most, if not all, the estimates of allowances. It is clear that the available data for infant nutrient recommendation do not provide the objective foundation needed for the management of finite social resources. Finally, the RDAs do not address the upper limit of nutrient intake consistent with health. In an affluent society, this boundary of recommended allowances may prove to be more important than the delineation of adequacy of the diet.

When such an analysis of the existing dietary recommendations is made of the data base for childhood and adolescent requirements, it is found that almost without exception these allowances are an extrapolation of infant and adult recommendations. The major exception is the case of energy allowances which are based upon average intakes and basal expenditures.

II. THE NEED FOR RESEARCH TO DEFINE DIETARY STANDARDS

It is clear from the preceding paragraphs that there is a need for more precise information concerning nutrient requirements of infants and children and that the existing data, although of value historically, are not adequate to provide for this need.

Beginning from first principles, the nutrient requirements of infants and children include two broad but inter-related needs: those for growth and those for

maintenance of optimal function. Growth is a primal biological function which can be defined as the action or process of increasing gradually in magnitude, quantity or degree (Ox.). In this discussion we modify the more restrictive definition of Cheek; the physiological accretion of new tissue which is reflected by the acquisition of protein, fat and water. Biological growth represents the final expression of cellular events expressed as hyperplasia, hypertrophy and differentiation. The maximal growth achieved is an expression of genetic potential channeled through these mechanisms as modulated by the resistance of environmental factors. In the human, it has now been demonstrated that nutrition is the major environmental variable influencing growth. If growth is symmetrical, it can be expressed as a mathematical relationship: $\text{mass} = a - b_e^{-At}$. Growth, however, in the human is not symmetrical because of environmental factors which determine the rate and mode of storage of nutrients. This asymmetry is due to the storage of fat calories. One calorie accumulated in active tissue is associated with one gram of weight gain, one calorie stored in adipose tissue is associated with 0.15 gm of weight gain. It is evident that weight gain under these circumstances represents a composite of the gains of specific organs and tissues and that the mechanisms which direct available nutrients into these tissues determine the distribution of the accreted calories between high and low caloric density tissues. The practical implications of this principle should be readily apparent when it is realized that the major criteria for normal protein and caloric intake is growth. There have been very few investigations related to macronutrient intake which accounted for variations in body composition. One such study demonstrated that on a similar calorie intake, breast milk feeding led to fatter babies and cow's milk feedings led to larger active tissue mass. The logical question is: are bigger babies better or are fatter babies fitter? A definition of normal and/or optimal growth is essential to the understanding of adequacy of childhood nutrient intake. These are only grossly approximated by estimates of weight and height. They require estimates of specific tissue mass if precision is to be obtained.

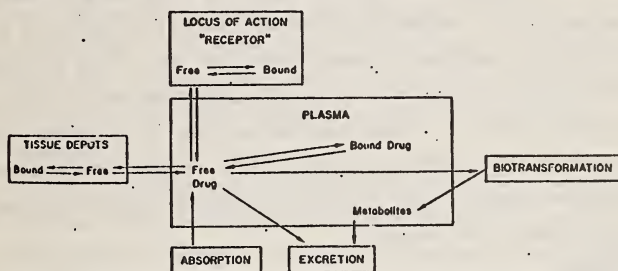
A related approach, which is in actual fact a refinement of the above method

for evaluation of nutrient requirements, is the factorial or balance method by which the retentions within the body are estimated by careful measurement of nutrient intake and excretion. A basic and seemingly insurmountable barrier to precision in this method is the fact that retentions always exceed reasonable estimates of growth. The investigator is faced with "the case of the missing nutrients" thus unaccounted for in the gap between "retention" and change in body composition. The first problem is that discussed above, what was the quantitative nature of the change in body composition called growth? The second problem is basic to the study of any chemical system, what were the products of the reaction? There has never been a systematic study of the products of human macronutrient metabolism. To be determined precisely, an internal standard of the nutrient under study must be used to determine the recovery rate of nutrient metabolic products. This can only be done with stable, non-radioactive tracers in normal subjects. Part of the lack of precision in the factorial method is due to inability to accurately measure excretion. No chemist should be satisfied with his study of an exergonic process unless he can account for all of the products.

The discussion to this point has focused upon the structurally important macronutrients. We have emphasized the importance of the measurement of growth as a function of the accumulation and distribution of calories and active tissue mass. In reality, the structural mass of the body is the structural capacity for essential micronutrients and intermediary metabolic products. The adequacy of any nutrient depends upon the satisfaction of functional capacity by the available product. The functional capacity may be identical with the structural capacity, as in the example of serum transferrin, or may be modulated by the interaction of other nutrients, as in the interdependence between protein adequacy and Vitamin A. When viewed as a biophysical model, there is a cascade of saturable capacities or "pools" which, depending on the nutrient, are involved in the absorption, transport, tissue storage and excretion of each nutrient. Adequate nutrient intake can be described under ideal conditions as that quantity of dietary intake which allows the functional saturation of tissue capacity. Toxicity can be visualized as the oversaturation of the physiologic

capacity with a displacement to other secondary pharmacologic pools.

Although the estimation of body composition is a first step toward the definition of nutrient capacity, it is evident that precise estimate of nutrient capacity must be based upon a study of specific pools and their saturation kinetics. In reality, the study of nutrient adequacy is closely related to the field of pharmacodynamics. The major difference lies in the size of the "bound" tissue depots of macronutrients which is much larger than that of most pharmacologic agents. This is due to the structural role of macronutrients. The macronutrients also participate in fluxes associated with turnover of specific structural units. A general scheme of the metabolism of nutrients parallels that of drugs.



This is from a pharmacology text and needs only slight modification for application to the study of physiologic nutrients. There are four factors which modify this scheme in infants: 1) variation in anatomical capacity ("tissue depots"), 2) differentiation of functional capacity ("tissue and plasma binding"), 3) immaturity of the digestive tract and 4) immaturity of metabolic and renal excretory mechanisms.

In a quantitative sense, nutrient adequacy can be determined as that amount of nutrient which satisfies the capacity of the primary physiological systems and this is dependent on adequate saturation of absorptive and transport systems. Toxicity occurs when the primary capacity is exceeded and secondary systems interact with the nutrient. This, however, is not a linear system but a complex biophysical function. One of the most striking characteristics of adsorption of molecules onto protein is that they do not follow the laws of mass action. This dictates the need for specific

and sensitive methods for determining micronutrient-apoprotein interaction. This is true whether the nutrient system is water-actomysin; zinc-alcohol dehydrogenase or thiamine-pyrophosphate-aldehyde transferase.

One of the characteristics of the above reactions is that they are cellular in domain. In a simplified view, nutrient adequacy is a combination of cellular capacity and cellular saturation. Cellular capacity can be approached by improved quantitation of body composition. Cellular saturation can be best documented by the study of cells from the human body. It is probable that this can be approximated by the measurement of tissue pools, however, precision requires that cellular function be examined. This is possible for specific tissues from normal subjects: hair, nails, squamous epithelial cells, red and white blood cells and in small samples of skeletal muscle or adipocytes. Additional information from within the cell may be available by a collection of merocrine and holocrine secretions which have not yet been studied from the nutrient point of view. Experience from the study of the cellular elements in milk suggest that it is possible to harvest cellular fragments from such secretions for detailed metabolic study. Extensive opportunities exist for the study of fetal tissues present in the placenta.

III. RESEARCH

Children's nutrition research should be focused on the nutrient requirements during the periods of growth. This begins at conception and extends through adolescence. Maternal nutrition is of importance as it relates to conception, fetal growth and growth during lactation.

Although this scope of applied research is a narrowed view of the field of nutrition, it still represents an extensive field. It is concerned with the nutrient requirements of nearly half of the population of the United States. It covers the growth period which has transcendent influence on mature stature and function. It is doubtful that even a massive research effort such as that of the NIH cancer program could fully encompass this field. The fundamental knowledge in the field would not support such a massive effort, neither could it be implemented from existing resources. These limitations dictate that priorities must be developed if

meaningful contributions are to be achieved. This strategy is developed in the following paragraphs.

A. Time Span

In viewing growth as a process, it is evident that an infinite number of intervals could be examined. Growth, however, is a negative exponential process with a deviation at puberty. Human growth is unique in that the period from weaning to adolescence is delayed in time when compared with that of sub-primate mammalian species. In this regard it resembles a step function of two exponents. The basic changes in rate of growth are found in the first two years of prenatal and post-natal life and the first two years of adolescent growth. The scope can be further limited if these two key areas are accepted as the primary areas of involvement. Primary emphasis will be given to the period of infancy in the first ten years of effort because of methodologic considerations.

B. Nutrients

In the introduction, a list of thirty different nutrients was reviewed. All of these require investigation if the objective of precise nutrient recommendations is realized. This should be approached initially by emphasizing the structural nutrients. The requirements of protein, calories, water and calcium determine the structural capacity of the body which, in turn, determine the physiologic requirements of the micronutrients. These structural nutrients make up more than 98% of body weight; water 70%, protein and fat 24%, and calcium 4% of body mass. Unless the structural capacity can be estimated with precision, the functional nutrients which make up the remaining allowances on Table I cannot be accurately investigated. This primary scheme does not preclude simultaneous work on functional nutrients. It is anticipated that future estimates of functional nutrient requirements can be based upon their relationships to these structural nutrient intakes. This approach has already been adopted for the existing RDA for thiamine, ribo-

flavin and niacin. Similar ratios to nitrogen have been developed for potassium. Phosphorus has been viewed in relationship to calcium retentions.

C. Level of Science

A final priority rating must be made in regard to the level of science at which these studies are to be pursued. The scientific method has been classified by Whitehead into fundamental and superficial investigations. The superficial approach is not consistent with the problem orientation outlined in this document; it consists in the development of piecemeal insights into processes based upon a reorganization of existing thought and methods. The fundamental approach must be directed by a clear statement of objectives if it is to be relevant to human needs. It does, however, allow for a systematic, organized approach to the solution of problems with sufficient priority to justify this approach. In the development of nutrition research priorities, the objectives of precision in the estimate of nutrient requirements necessitate an investment in new and improved methodologies. These fundamental approaches are the products of advances in more basic areas of physics and chemistry which have allowed the application of a more precise approach to the solution of problems in the applied science of nutrition. The fact that the subjects of such study are children further taxes the fundamental sciences for the development of methodologies for safe human investigation.

In recent years there has been much emphasis on application of existing medical knowledge in the improvement of human wellbeing. This has been used as an argument against fundamental research. In the area of childhood nutrition, this argument is not relevant because the fundamental knowledge is not in existence. Arguments are heard emphasizing the importance of nutrition in health planning and health practice; the fundamental impediment to the realization of such an emphasis is the need for precision in the knowledge of nutrient requirements.

D. Normal Subjects

While the objective of this childhood nutrition research must be the study of normal nutrient requirements, some investigations need to be conducted in abnormal children. Normality is a statistical concept representative of a gaussian distribution of attributes. This concept, though useful in aggregate, is not effectively applied to the individual child. In reality, all "healthy" children are abnormal, some more than others. The alternate approach to evaluation of nutritional status uses the "non-parametric" evaluation of covariance of attributes. In order to increase the range over which covariance is studied, it is necessary to extend the line of observations from the relatively healthy subject to the "ill". As in the field of endocrinology, the extreme nutrient disturbance provides a perturbation of the normal mechanisms which allow insight into nutrient interactions with each other and with body composition. An additional asset resulting from the study of the extreme nutrient disturbance is the fact that experiments can be more easily justified in sick children if they can be of benefit to the individual subject. This intermediary test of clinical methodology is essential before similar studies are conducted in the well child who receives no personal benefit from the investigation.

IV. NATIONAL OBJECTIVES OF CHILDREN'S NUTRITION RESEARCH

A. General

The development of the scientific bases for standards of nutrient intake and nutritional status in infants and children.

B. Specific Research

1. The development of precise methods for the investigation of nutrient requirements in infants.
2. The development of methods for the investigation of the relationship between nutrition and growth in infants.
3. Definition of nutritional requirements for optimal growth and anthropometry.

4. Definition of nutritional standards for dietary intake.
 5. Definition of biochemical standards for nutritional surveillance.
- C. Related research
1. Determination of the effects of physiologic stresses on nutrient requirements.
 2. Determination of the effects of acute infection on nutrient requirements.
 3. Determination of the effects of chronic diseases on nutrient requirements.
 4. Determination of the effects of environmental contaminants and pollutants on nutrient requirements.

V. METHODS OF PROCEDURE

The comprehensive approach to the specific objectives outlined can be discussed in several dimensions; the requirement to be determined, the processes underlying the definition of requirement and the technical methods utilized for meeting these objectives. The first two describe the biological approach to these objectives and the latter describes the biophysical techniques to be utilized in these efforts. Obviously, there is great overlap between these parameters of investigation. For clarity of organization, we will deal with them individually.

The field of infant nutrition can be subdivided into a matrix of six nutrient requirements and six processes as outlined in Figure 2. These divisions allow us to define systems for investigation and scientific management.

A. Nutrient Requirement Identification

The rationale of approach to the large variety of nutrient requirements has been described in preceding sections. They are tabulated along the ordinate of Figure 2 in descending order of priority. The first four define the structural requirements of protein, calories (non-protein), water and calcium. The fifth division is the study of micronutrients; the vitamins and minerals which regulate function. The sixth division is the study of

stress. There is much evidence that the stress of acute illness or the interaction of environmental agents plays a significant role in determining the individual variations in nutrient requirement.

B. Process Identification

In discussing nutrient requirements, it is reasonable to ask "adequate for what?". In our concept, nutrient adequacy is linked to a physiologic saturation of the following biological processes (Table II).

Significant external variables in infant nutrition are the quantity and composition of diet. Indirectly or directly, human milk is an integral part of normal infant nutrition. Directly in the infant of a lactating mother and indirectly in the formula fed infant who is dependent upon our knowledge of human lactation for his cow's milk based infant formula. The importance of study of human lactation is underscored by the fact that 17 of the existing nutrient recommendations for the infant by the RDA are based upon human milk intake. The literature on subprimate mammary secretions is extensive, that on human lactation as a biological process is scanty. The nutritional basis for successful lactation is inseparable from the problem of infant nutrient requirements. The data on this subject is not comprehensive nor systematic. The study of the process of human lactation is an important foundation for infant nutrient investigation.

In the family setting, there is an intimate relationship between the alveolar lactating cells and the absorptive enterocytes. The parallelism in function is a product of genetic selection as old as mammalian life. Neither cellular line functions in isolation from the interactive control of the other and both have specialized functions which complement each other. It is reasonable to state that the lactating cell is the essential regulant of the nutritional input but the absorptive cell is the first rate limiting barrier to nutrient utilization: an understanding of the variations in the process of digestion and absorption in response to varied sources of milk

and solid diet is a second process essential to the development of clear nutrient recommendations for infancy.

The process of transportation of absorbed nutrients to and into the cells is an essential intermediary step in nutritional adequacy. The saturation of transport proteins and cells and the presence of alternate excretory pathways such as bile and urine determine the availability of absorbed nutrient to the end organ cells. The process of cellular uptake and the specific mode of action of the micronutrients also determine the adequacy of nutrients in cell function.

It is important to ask of nutrient recommendations whether they suffice for maximal efficiency of cell function. As previously discussed, the maximal saturation of the cellular physiologic capacity is conceived as an operational definition of nutrient adequacy. The qualifications imposed in this generalization are discussed elsewhere. In the context of this biophysical approach to nutrient adequacy, it becomes essential to examine cellular functional saturation. The routes to practical implementation of this plan are also discussed in the introduction. Here, we will discuss the stages in cellular function which need investigation in human cells, in vivo and in vitro.

The process of cell development is composed of growth and differentiation. Growth can take place by hyperplasia and/or hypertrophy. A large literature has developed concerning the regulation of tissue growth in under and over nutritional states. This is an important area for continued investigation in the human, however, there is no quantitative data on the relationship of these concepts to nutrient requirements. In addition, the control of differentiation is a field which has not been approached by the nutrition community. It is an essential area for investigation because it relates to the physiologic capacity of the cell whereas growth in mass is restricted to cellular structural capacity. Because maturation is a unique feature of childhood nutrition, it acquires a major emphasis.

The continual renewal of cell structure and its functional units is univer-

sal in the field of biology. We have designated this as the process of cell flux. There is evidence that cell flux is not a static function but changes with age. The protein turnover in infants is 16 gm/Kg/day, but only 3.0 in adults. An adequate formulation of nutrient recommendations must include an estimate of the cell fluxes which may or may not be a part of cell development during the maturational process.

The processes of control of cell development and flux by nutrient availability may be mediated by direct cellular interaction or by intermediary interactions by homeostatic control tissues including the liver and endocrine organs. The participation of these damping mechanisms in cellular control processes emphasize the need for the study of in vitro systems utilizing human cell lines for delineation of cellular functional requirements and their testing in vivo.

The processes described in these paragraphs are those that make up the total nutrient requirement. The estimate of total allowance is as precise as our ability to define these subsets in terms of the saturation of these various pools at the integrated and cellular levels.

c. Methodology

1. Clinical. In our society the majority of infants are born in hospitals. Studies in the perinatal period must be associated, therefore, with substantial clinical facilities.
2. Structural Nutrients. Because the present data are based upon balance studies, this method must provide the baseline data against which more innovative studies are tested. Whole body calorimetry provides a test of active tissue function, total body potassium by the K^{40} technique and total body Ca, N and Cl by activation analysis can also help define anatomical capacity in cadavers from children. The use of stable isotope internal standards is essential to improve the precision of the factorial or balance procedure. These can now be

determined by mass measurements and eventually by NMR imaging.

3. Functional Nutrients. The composite features of nutrient absorption, transport, storage and secretion must be determined in a context of defined capacity. Capacity will be defined by study of structural nutrients. All nutrients, including the structural nutrients, must be studied by measurement of the extracellular processes through stable isotope kinetic studies. An estimate of intracellular processes is possible through these same mechanisms, however, the study of adequacy for optimal cell function requires the study of specific functions in vivo and in vitro. A long term study of the kinetics of human cell saturation in vitro is projected towards this end. The availability of tissues obtained during unrelated surgical procedures is essential to this objective.

4. Cultural. In cooperation with epidemiologists and behavioral scientists, a program for evaluating the cultural impact on normal nutritional status must be instituted. This can provide the transition from laboratory to field studies envisioned as an ultimate objective of children's nutrition research.

TABLE I

ANALYSIS OF RECOMMENDED DIETARY ALLOWANCES FOR INFANTS

BASIS OF RECOMMENDATION							
NUTRIENT	DISCUSSION OF INFANT REQ.	BALANCE OR FACTORIAL	INTAKE	GROWTH AS END POINT	OTHER AS EMPIRICAL	PRECISION OF ESTIMATE	PAGE* NO.
Water	No	X				None	21
Energy	Yes		X	X		Poor	32
Protein	Yes		X	X		Poor	41,47
Essential Fatty Acids	No	-	-			None	49
Vitamin A	Yes		X			None	53
Vitamin D	Yes		X	X		None	54
Vitamin E	Yes		X			Fair	60
Vitamin K	Yes				X	Fair	62
Ascorbic Acid	Yes		X			Poor	64
Choline	Yes					None	65
Thiamine	Yes	X	X			Poor	67
Riboflavin	No	-	-			None	68
Niacin	Yes		X			Poor	71
Folacin	Yes		X			Poor	73
B ₆	Yes		X		X	Poor	77
	Yes		X			None	79
Pantothenic Acid	Yes		X			None	80
Biotin	No	-	-			None	81
Calcium	Yes		X			None	86
Phosphorus	Yes		X		X	None	87
Magnesium	Yes		X			None	89
Sodium	Yes		X			None	89
Potassium	No	-	-			None	90
Chloride	No	-	-			None	90
Iron	Yes				X	Good	94
Copper	Yes	X				Fair	96
Iodine	No	-	-			None	97
Fluorine	No	-	-		X	None	98
Zinc	Yes		X			None	101
Chromium	No	-	-			None	101
Other Trace Elements	No	-	-			None	102

*Recommended Dietary Allowances, National Academy of Sciences, 1974

TABLE II
CHILDREN'S NUTRITION RESEARCH

I. REQUIREMENT

- a. Protein
- b. Calories
- c. Water
- d. Calcium
- e. Micronutrients
- f. Effects of stress

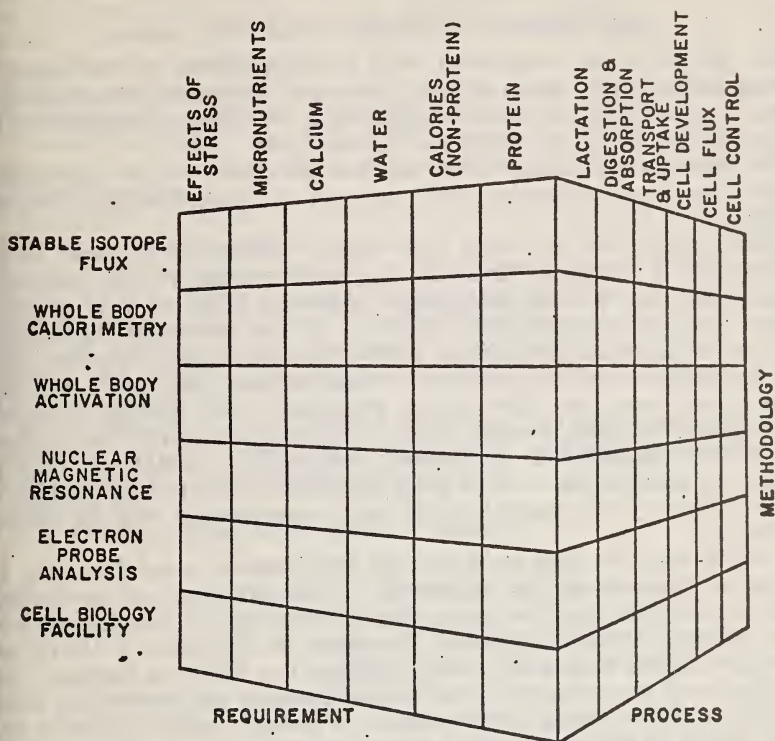
II. PROCESS

- a. Lactation
- b. Digestion and absorption
- c. Transport and uptake
- d. Cell development
- e. Cell flux
- f. Cell control

III. METHODOLOGY

- a. Whole body activation
- b. Whole body direct calorimetry
- c. Stable isotope pool measurement
- d. Electron probe analysis
- e. Nuclear magnetic resonance
- f. Cell biology facility

FIGURE 2 FIELD OF INFANT NUTRITION



Mr. WAXMAN. Thank you. Dr. Owen.

STATEMENT OF GEORGE M. OWEN, M.D.

Dr. OWEN. I am associated with the University of Michigan. I would preface any remarks to say that my comments represent my own views. I am not here representing or offering testimony in behalf of the National Nutrition Consortium.

Dr. Nichols did share with me his schedule of the day and I appreciate your extending your time to accommodate my late arrival.

Dr. OWEN. The fact that the written testimony is brief is no indication of a lack of interest in the intention of the proposed legislation. My written testimony addresses itself to four general areas that are covered or alluded to in the proposed legislation.

First of all, I think there is solid evidence which indicates that the nutritional state in which a woman enters pregnancy and her nutritional care and diet during pregnancy and during lactation confer clear health benefits both to the woman and to her infant.

I have indicated her nutritional state during lactation. That is simply to summarize in that brief statement that breast feeding is under ordinary circumstances the most appropriate way for babies to be fed.

I think that we also have enough information available both in terms of recognizing the magnitude of the problems, of predicting their occurrence, and the means for preventing the development of two common nutrition-related disorders in children. I think we have the ability to predict which children are likely to become iron deficient and we certainly have the mechanism for preventing that. I think we have enough information to predict which children are most likely to develop obesity either in infancy or in later childhood, and I think we have the capability available now to prevent that from occurring.

I agree with Dr. Nichols' comments that the fragmentation of health care services contributes significantly to our inability to properly implement strategies to preclude development of these two common nutrition related disorders in children. Second, having been involved in a national study of preschool children and some other studies involving populations of children in selected States and being aware of activities in the 10-State survey and in the Hanes survey, it's clear that to effectively coordinate health care services for women and children, particularly in relation prevention of nutrition disorders, that we need to have better information available on a State-by-State basis. Needs assessment in terms of identifying what the problems are, the magnitude of those problems, what services exist presently, how those services are utilized and what gaps exist should be looked at on a State-by-State basis.

I think that we have nutrition councils and health system agencies in all States. They ought to provide a fair amount of information upon which we could build using some standardized approaches to really get at the question of what the needs are.

Third, maybe the time is ripe for some legislation to effectively increase the amount of funding in research specifically in terms of methods for evaluating nutritional status application of and to develop mechanisms for assuring quality control in those methods

and procedures. There are several systems outside of the CDC surveillance system that can be effectively utilized to get at some of the questions that other panelists were addressing and which would be of considerable help to examine the problems, store, retrieve, analyze, interpret, and report data, which gets at the whole issue of evaluation of the effectiveness of programs.

I would certainly agree that attempting to build in evaluation and need for annual or biannual reporting in terms of outcomes is highly desirable.

Fourth, in the area of communications of nutrition information, this committee should be reminded or be re-reminded that the National Nutritional Consortium represents about 80,000 professionals in the nutrition area. The consortium is beginning to demonstrate some achievement of stated goals, namely, to create more effective communications between constituent organizations comprising the consortium and to coordinate some activities in the educational area.

In this sense the consortium represents a manpower pool that hopefully will be increasingly effectively utilized in the area of communications of nutrition information.

Thank you.

[Dr. Owen's prepared statement follows:]

STATEMENT OF GEORGE M. OWEN, M.D., ANN ARBOR, MICH.

Mr. Chairman and Members of the Committee, I am pleased, as a pediatric nutritionist, to have this opportunity to comment briefly on HR 4362 "Maternal and Childhood Nutritional Disorders Prevention and Information Act." During the past 20 years, I have been involved in teaching and research related to diet, nutrition and growth of infants and children. During the past 10 years, my professional interests and activities have moved increasingly in the direction of preventive health services in which I see nutrition occupying a central and pervasive role.

My comments relate to 4 areas in the proposed legislation. First, it is clear that entering pregnancy in good nutritional status and maintaining good maternal nutrition from the time of conception through lactation will confer significant health benefits on the mother and on the fetus and the infant during the first year of life. These are critical periods where money spent on prevention and maintenance will be cost-effective.

We have the information and means available to achieve and maintain adequate iron nutriture during infancy, and to avoid development of iron-deficiency anemia. Although we do not know if infantile obesity necessarily leads to adult obesity, available evidence fails to indicate any advantages of obesity in infancy. We have knowledge of relative importance of hereditary and environmental factors affecting growth and body composition and have some acceptable technics for evaluating growth and relative fatness. We should therefore be able to effectively anticipate the likely development of obesity and to recommend appropriate strategies to avoid it.

Second, it is certainly desirable that federal agencies coordinate their activities relating to development of nutrition information. Mechanisms for ongoing monitoring and surveillance of nutritional status already exists, but are limited in scope and are focused on high risk low income segments of the population in only half our states. Both the quantity and quality of data on nutritional status of the general population vary considerably

from state-to-state. Needs assessments in each state should be made using standardized technics in order to determine more precisely what problems exist and their magnitude and to determine what services already exist, how they are functioning, what groups are being served and to identify gaps in such services in both the public and private sectors. Health systems agencies and state nutrition councils should have substantial information upon which to build to develop comparable needs assessments in each state.

Third, substantial additional support for research is needed to develop new technics and to refine existing methods for nutrition screening and assessment. These technics must be generally available, standardized and systems developed to ensure quality control. The lipid standardization program at the Center for Disease Control (CDC) is a good example of such a quality control system for a laboratory procedure. Similarly, development of the National Center for Health Statistics Growth Charts by NCHS and CDC and their recommended use as the reference standard allows comparisons and evaluations of growth data collected by health professionals. CDC surveillance systems can serve as models for future development of coordinated systems for uniform storage, retrieval, analysis and reporting of information on nutritional status.

I would like to remind the members of the committee that the National Nutrition Consortium (NNC) is an organization comprising the major professional organizations in food, nutrition and dietetics in the United States. Cumulative membership of these organizations totals approximately 80,000 nutrition scientists, physicians, educators and dietitians who have education, expertise and experience in nutrition. The Consortium is enhancing communication among its member organizations and is attempting to coordinate, complement and strengthen their activities, but not duplicate their functions. Although I am a member of The Board of Directors of the National Nutrition Consortium (NNC), my testimony today represents personal opinions and not those of the NNC. However, the resources of the NNC should be used to assist in communicating nutrition in a coordinated manner.

Mr. WAXMAN. Thank you very much.

If I might, I would like to ask a few questions so we could have it in the record.

What percentage of American children are affected by nutritional disorders, iron-deficiency anemia, obesity, or dental caries? Do you have any figures on that?

Perhaps you can submit some figures to us at a later time for the record.

Dr. OWEN. I have looked at three major areas, partially the increasing occurrence of pregnancy in teenagers and the much greater likelihood of low birth offspring. Approximately one-sixth of the babies born in this country are going to be born to adolescents and we know there is about a 15-percent chance of low birth. This is to a considerable extent nutrition related.

I think iron deficiency anemia as demonstrated by low hemoglobin or hematocrit levels is still of the order of magnitude of 10 to 15 percent in late infancy and very early preschool age group in the low-income segments of the population. I don't know what the prevalence is in terms of adolescents.

Obesity is somewhat difficult to define, but using weight-for-height percent of standard, I think somewhere around 20 to 25 percent of children are obese, although probably not more than 5 percent are frankly obese.

Now the extent to which those are all independent occurrences is another problem. For example, we know that low birth means some greater likelihood of becoming anemic as older infants. But I would guess mixing together those three areas, probably 25 or 30 percent of the infant childhood population is either significantly at risk or has some demonstrated nutrition-related disorders.

Mr. WAXMAN. Thank you very much.

Mr. Leland, do you have some questions?

Mr. LELAND. Mr. Chairman, I would like to ask for consent to include H.R. 4362 in the hearing record and to obtain written comments on it from a number of Government and non-Government groups.

Mr. WAXMAN. Without objection.

[Testimony resumes on p. 326.]

[The text of H.R. 4362 and written comments thereon follow:]

96TH CONGRESS
1ST SESSION

H. R. 4362

To increase the quality, effectiveness, and availability of nutrition information and programs for the prevention of nutritional disorders in children and women, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JUNE 6, 1979

Mr. LELAND (for himself and Mr. MAGUIRE) introduced the following bill; which was referred jointly to the Committees on Interstate and Foreign Commerce, Agriculture, and Ways and Means

A BILL

To increase the quality, effectiveness, and availability of nutrition information and programs for the prevention of nutritional disorders in children and women, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 SHORT TITLE

4 SECTION 1. This Act may be cited as the "Maternal
5 and Childhood Nutritional Disorders Prevention and Infor-
6 mation Act of 1979".

FINDINGS

SEC. 2. The Congress finds that—

(1) nutritional disorders (A) are particularly widespread among pregnant women and children, (B) are a major factor in human morbidity and mortality, and (C) are treatable;

(2) hereditary metabolic disorders and conditions are the second most frequent cause of death in infants prior to one year of age, one such condition is mental retardation, and the consequences of such disorders and conditions may be controlled through early screening, counseling, and dietary treatment;

(3) Federal programs for the prevention and treatment of the disorders and conditions referred to in paragraphs (1) and (2), for research into such disorders and conditions, and for providing information respecting such disorders and conditions are uncoordinated, duplicative, and unfocused; and

(4) a major improvement in such Federal programs would occur through focused nutrition research, through improvement of uniform nutrition recommendations, through intensified nutrition education and information programs, and through the development of coordinated programs to identify, assess, and treat individuals vulnerable to nutritional disorders.

1 PROGRAMS TO DETECT, ASSESS, AND TREAT MOTHERS
2 AND CHILDREN VULNERABLE TO NUTRITIONAL DISORDERS

3 SEC. 3. (a) The Secretary of Health, Education, and
4 Welfare shall through existing programs under the Social Se-
5 curity Act and the Public Health Service Act—

6 (1) develop scientific diagnostic procedures and
7 guidelines to assess human nutritional status and
8 detect childhood metabolic hereditary disorders;

9 (2) develop regional centers for the detection of
10 metabolic hereditary disorders in newborn infants and
11 for the dissemination of information concerning the ap-
12 propriate dietary treatment of such disorders; and

13 (3) develop programs to locate, assess, and estab-
14 lish referral procedures for treatment of children and
15 pregnant women vulnerable to nutritional disorders and
16 to inform pregnant women of the proper nutrition and
17 the adverse effect of alcohol consumption during
18 pregnancy.

19 (b) Not later than twelve months after the date of enact-
20 ment of this section and annually thereafter, the Secretary of
21 Health, Education, and Welfare shall report to Congress on
22 the activities conducted under subsection (a).

1 DEVELOPMENT OF HUMAN NUTRITION INFORMATION

2 SEC. 4. (a) The Secretary of Health, Education, and
3 Welfare and the Secretary of Agriculture shall jointly and in
4 consultation with appropriate scientific entities—

5 (1) develop efficient coordinating mechanisms to—

6 (A) enhance their respective human nutrition
7 research activities,

8 (B) minimize duplicative human nutrition re-
9 search activities, and

10 (C) develop systems for the uniform storage
11 of information on human nutrition and bioavaila-
12 bility of nutrients and systems for the retrieval
13 and integration of such information;

14 (2) develop research programs to determine
15 human nutrition requirements for optimal fetal, perina-
16 tal, and childhood development;

17 (3) develop nutrition and dietary guidelines for
18 children, pregnant women, and other age groups for
19 which such guidelines may be appropriate;

20 (4) measure the effect of current programs de-
21 signed to provide supplements to the diet of infants and
22 pregnant women; and

23 (5) develop uniform nutrition recommendations to
24 promote optimal health and prevent nutritionally relat-

1 ed diseases and for use in providing nutrition to pa-
2 tients undergoing medical treatment.

3 (b) Not later than twelve months after the date of the
4 enactment of this section and annually thereafter, the Secre-
5 tary of Health, Education, and Welfare and the Secretary of
6 Agriculture shall each report to the Congress on the activi-
7 ties conducted under subsection (a).

8 COMMUNICATION OF NUTRITION INFORMATION

9 SEC. 5. The Secretary of Health, Education, and Wel-
10 fare, in consultation with the Federal Trade Commission and
11 individuals and entities skilled in advertising, marketing of
12 products, and opinion surveys, shall enter into contracts for
13 the development (on a competitive basis) of—

14 (1) announcements to be broadcast, without com-
15 mercial sponsorship, over radio and television—

16 (A) to present to children and the general
17 public information concerning the relationship be-
18 tween diet, exercise, nutrition, and health, and
19 other information developed under section 4 of
20 this Act,

21 (B) to present to women information con-
22 cerning the relationship of medical care and good
23 nutrition and the adverse effect of alcohol con-
24 sumption on the course and outcome of preg-
25 nancy, and

- 1 (C) to present to women information con-
- 2 cerning the relationship of breast feeding to the
- 3 well-being of the infant,
- 4 (2) programs and strategies that will promote
- 5 better consumer comprehension of food label informa-
- 6 tion and the use of that information in attaining opti-
- 7 mal health; and
- 8 (3) other means to improve the nutritional status
- 9 of children, women, and the general public.

RESEARCH
EDUCATION
PUBLIC AFFAIRS



1750 K STREET, N.W. WASHINGTON, D.C. 20006
TEL (202) 452-8444 CABLE FMIUSA WASH DC

June 20, 1979

The Honorable Henry Waxman
Chairman, Subcommittee on Health
and Environment
House Committee on Interstate and
Foreign Commerce
2415 Rayburn House Office Building
Washington, D.C. 20515

Dear Congressman Waxman:

The purpose of this letter is to comment on H.R. 4362, the
"Maternal and Childhood Nutritional Disorders Prevention
and Information Act of 1979."

There is a great need to provide more and better information
regarding maternal, infant and child nutrition to the general
public and specific, vulnerable target populations. There is
certainly enough scientific data to confirm the importance of
preventive programs in this area and their potential for
positive, long-term benefits on the reduction of mental and
physical disorders controllable through dietary treatment.

H.R. 4362 attempts to improve and expand the means of communicating
the particular importance of proper nutrition in children and
pregnant women through existing programs and better interagency
coordination of nutrition research and information. The concept
of this proposed legislation is certainly commendable.

Sincerely,

Karen H. Brown
Vice President,
Consumer Affairs

KHB/nkb

GIANT FOOD INC.

BOX 1804, WASHINGTON, D. C. 20013
(301) 341-4365

CONSUMER AFFAIRS OFFICE

June 21, 1979

The Honorable Mickey Leland
Member of Congress
Congress of the United States
House of Representatives
Washington, D. C. 20515

Dear Congressman Leland:

Thank you very much for sending me a copy of H.R. 4362. While we at Giant are generally in the favor of programs designed to increase the quality, effectiveness, and availability of nutrition information in the marketplace, we do not feel that we can specifically comment on the proposed bill. Generally, it appears to encompass a great many topics which need to be defined much more specifically as to goals and priorities.

However, we support the concept of H.R. 4362 to coordinate Federal efforts ultimately aimed at increasing consumer knowledge and promoting optimal health. We support strategies that will improve consumer understanding of the relationship between diet and health as well as the communication of nutrition information to consumers.

I certainly appreciate your contacting Giant. I regret that I cannot be more specific in my comments, but your letter was not received until June 19.

Sincerely,



Odonna Mathews
Consumer Advisor

OM:abh

Woman's Day

1515 BROADWAY
NEW YORK, NEW YORK 10036
(212) 975-7880

GERALDINE RHOADS
VICE PRESIDENT
AND EDITOR-IN-CHIEF

July 5, 1979

The Honorable Mickey Leland
House of Representatives
Washington, D.C. 20515

Dear Mr. Leland:

Mr. Jay Burzon has passed along your letter regarding H.R. 4362, designed to improve nutrition information programs.

You might be interested to know that Woman's Day interest in this has prompted me to start a new feature this fall-- the inclusion of calorie and important nutrient counts on all recipes in the magazine. Woman's Day will be the first magazine in the field with a program like this.

With our good wishes to you in your efforts along these lines,

Cordially,

Geraldine Rhoads
Geraldine Rhoads

Baylor College of Medicine
DEPARTMENT OF PHYSIOLOGY • 713 790-4700



The Honorable Mickey Leland
1207 Longwood House Office Bldg.
Washington, D.C. 20515

Dear Mr. Leland:

It was indeed an honor to testify in behalf of HR-4362 on June 11th. This letter is to respond to the questions that you submitted in writing after the hearing on that date. The following represents my best opinion in response to your specific questions:

(1) Would a nationwide campaign against alcohol abuse by women of childbearing age, as suggested in this bill and earlier by Mr. Califano, be a worthwhile endeavor? Answer: Yes. Question: Are public service announcements the way to go? Answer: This may be a very valuable approach; however, the approach should not be limited to this effort. I believe that the evidence is clear that public service announcements have not succeeded in increasing the use of safety seat belts in automobiles. I suspect that the public service announcements should be part of a broader approach over a longer period of time.

(2) Nearly half the bills in Congress last year had in them some nutritional component. Would you take this as representative of the interests of the public for us to promote disease prevention legislation? Answer: This is one of a number of evidences that the public at large is concerned about nutrition and desires to have leadership from the medical and legislative community in this regard.

(3) The American Health Association recently warned doctors that it is prudent for even children to reduce cholesterol and fats since they feel atherosclerosis begins in childhood. Do you feel or know of any other nutrition-related diseases that begin in childhood? Answer: I am not convinced that children need to be on a low cholesterol diet during the period of time when they utilize a large amount of cholesterol for brain development and essential fatty acids are a key to the normal development of cell membranes. I believe that clear evidence should be given that a low cholesterol diet is not harmful to the infant or the lactating woman before this is recommended for all segments of the United States population. Osteoporosis and hypertension probably are degenerative diseases which have their origins in childhood. Here again we must be cautious not to overly interpret a national dietary goal so that children during the rapid growth phase before and after delivery and lactating women are not deprived of the essential nutrients because of their specialized requirements. A question frequently raised concerns the role of diet in the pathogenesis of cancer. There is inadequate evidence at this time to even consider the impact of any dietary intervention on the pathogenesis of cancer through intervening in the diet of the infant or pregnant or lactating woman. In summary, additional research is necessary before we can

safely apply these general dietary goals to the citizen of our country who has unique requirements for normal growth and development.

(4) Are not the RDA, the Recommended Dietary Allowances, all the information we need to obtain optimal health? Answer: The Recommended Dietary Allowances deal with the quantitative aspects of individual nutrients. They do not deal with the availability of the nutrients or the qualitative aspects of those nutrients.

Question: Why do we need other "nutritional recommendations"? Answer: The quality of the diet needs to be considered along with the quantity. The Recommended Dietary Allowances do not deal with the qualitative aspects of the diet for which we have increasing evidence linking items like salt and cholesterol to degenerative diseases.

(5) Would the clinical chemistry laboratory be the best training site for developing nutrition screening tests? Answer: The clinical chemistry laboratory should be a reasonable place to perform certain laboratory tests of a screening nature.

At the present time, many of the nutrient assessment tests are of greater value as public health tools than they are of diagnostic value to the individual subject. If clinical chemistry laboratories do become involved in nutrition screening tests, programs of standardization in conformity with national methodologies should be established so that national statistics could be derived from the data obtained at the local health center.

(6) What relation is there between infant formula and breast feeding practices in the health of the infant? Answer: Although infant formulas can be quantitative requirements for normal growth for the best known nutrients, there is increasing evidence that human milk has some qualities not available in prepared formulas. These qualitative aspects appear to play a role in the maturation of the gastro-intestinal tract and its immunity against foreign bacteria and viruses and foreign antigens. It is unlikely that these qualitative aspects can be safely identified, isolated and supplied in formulas prepared for infants at economically reasonable costs. Therefore, the best approach is to support human lactation or breast feeding as a national priority. One of the distressing features is that although 70% of west coast mothers now are breast feeding their infants to three months of age, this is almost entirely limited to the affluent population and the indigent population which could best utilize the protective effects of human milk, has not found it reasonable or possible to accept human lactation as the standard for infant feeding. This is a problem which should be remedied by the present legislation proposal. On the other hand, human milk is adequate only for a given period of time even in affluent societies. A time comes between the sixth and twelfth month of age when additional foods must be supplemented in order to maintain optimal growth and development. Weaning is the process of replacing human milk with semi-solid food as the infant matures to the point of eating at the table. The development of and the availability of sanitary weaning foods is a national priority and the industry producing these important intermediate foods should not be discouraged from marketing these products to the public. The question of adequate human lactation cannot be separated from the question of adequate weaning practices. They are both part of a continuity which starts with intrauterine nutrient supply and progresses through normal breast feeding up to the weaning table.

(7) Because this bill asks for more unified and coordinated federal nutrition research programs, would this legislation have a cost-saving mechanism built into it? Answer: A cost-saving mechanism would be ensured by this legislation only if it were truly able to coordinate these programs at the local level; it is my conviction that adequate resources exist with existing programs to meet the local need; however, the administrative constraints associated with the diverse number of programs, each with its own management directives, have limited the practical effectiveness of these action programs. As I stated in the transcribed testimony, this legislation could have a cost-saving mechanism built into it if it were child oriented rather than administrative-structure oriented.

(8) Dr. Nichols, I understand that you are Director of the Infant Nutrition Research Laboratory at Baylor which has been accused of having duplicated activities of the work at the National Institute of Child Health and Human Development. Would you comment on how better coordination could achieve far greater results in America? Answer: The National Institute for Child Health and Human Development has participated in organization of the Children's Nutrition Laboratory and in the review of scientific protocol now in effect in the Laboratory. The Scientific Director of NICHD attended a meeting on November 1st and 2nd at Baylor College of Medicine when the program was announced to the public and when scientists met to determine the priorities for initial research. In addition, Child Health and Human Development attends the Technical Advisory Committee meetings of the Laboratory. The first meeting was held subsequent to the hearings on the legislation on June 19th. A representative of Dr. Kretschmer was present and brought his personal greetings and best wishes to the advisory group. Furthermore, the Section of Nutrition and Gastroenterology at Baylor College of Medicine has received NIH funds including substantial grants from Child Health & Human Development for the past fifteen years. At the present time there is a contract for the study of the Food Technology of Human Milk funded by NICHD which complements the activities of the CNL as they apply to the study of nutrient requirements for human milk production. Furthermore, both NIH and the Department of Agriculture support the Children's Clinical Research Center at Texas Children's Hospital where investigations are underway on USDA-related protocols. In summary, I would never argue that better coordination cannot be achieved; however, I do feel that the accusation that there is a duplication of activities between the Children's Nutrition Laboratory and NICHD as stated in *Science* Magazine on June 8th, 1979, is absolutely incorrect and that the facts of the case can easily substantiate the high degree of coordination existing between this activity of the two departments.

(9) Does this legislation alleviate the USDA-HEW turf battle presently going on according to our present information? Answer: In the area of Childhood Research, there is no turf battle going on between USDA and HEW. However, it is important that a legislative base for coordination exists so that these efforts which are now ongoing to coordinate these programs have a sound legal basis. The existing basis is in the legislative language of the Appropriations Bill which requires cooperation between the Children's Nutrition Laboratory of the USDA and the National Institute of Child Health and Human Development of the NIH. It is very reasonable that there should be a very sound legal basis requiring this ongoing cooperation to be based on specific legislation. The legislation should also specify the levels of coordination in both policy development and specific research protocol implementations.

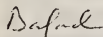
(10) Would you expect this to be resolved voluntarily? Answer: See the discussion of this point in the previous Paragraph No. 9. Question: Do reports from Congress help expedite this process? Answer: The reports to Congress should not be isolated from the reports regarding the action programs. The research should be seen in the context of national priorities in health delivery for children. The research should be mission oriented and directed toward the solution of key problems impeding implementation of the action programs. Isolated reports concerning research would never have the same mission orientation as a coordinated report from HEW and the Department of Agriculture concerning the parallel program in child health assessment programs and the various food and nutrition service feeding programs.

(11) How does this legislation tie into upgrading the WIC, Women, Infant and Children Supplementary Food Program? Answer: The current appropriations are three quarters of a billion dollars for the WIC program and would approach one billion dollars next year. The WIC program was designed to be a nutritional component of an overall health care system for children of the United States. If the CHAP Bill is passed, the appropriations are visualized as being approximately one quarter of a billion dollars or less than one half of the current appropriation for the WIC program. As experienced in Texas, and especially in Houston, an adequate program of child health delivery services is required before adequate implementation of the WIC program is possible. It is essential that the health services for indigent children in the United States be upgraded so that they match our investment in the WIC program. Not only must the two programs be balanced, but there must be coordination between the two programs so that they will be equivalent in their impact at the local level. This legislation, HR-4362, provides for the coordination of these two essential programs for improving child health in our country.

(12) Would you briefly comment on how this legislation might be further refined? Answer: This legislation needs to incorporate a detailed study of the existing CHAP Bill of Mr. McGuire and the other authorizing legislation which it seeks to coordinate. Greater specificity must be given to the mandate to HEW and the Department of Agriculture so that the report provided in response to this legislation will be relevant and meaningful to the natural objectives of providing better health for the children of this nation. I believe that Mr. Leland's Bill entitled "The Maternal and Childhood Nutrition Disorders Prevention Information Act of 1979" is complementary to the CHAP Bill; however, it would be ineffective unless the CHAP Bill were activated and adequately funded. The additional feature of HR-4362 is its inclusion of the use of mass media for the education of target populations concerning nutrition. I personally would like to see this broadened to include the entire spectrum of child health issues, including accident prevention, immunizations and recognition of the role of public education in health education so that the media programs would be coordinated with the programs in the school system.

Thank you for the opportunity to respond to these questions.

Yours truly,



Buford L. Nichols, M.D.
Professor of Pediatrics
& Physiology
Chief, Section of Nutrition
& Gastroenterology
Scientific Director,
Children's Nutrition Laboratory, USDA

Mr. LELAND. I would like to ask the panel: Will locating, assessing, and treating these patients for nutritional disorders offset higher cost of treatment later on?

Dr. NICHOLS. That's a management problem. That is very difficult to figure because we don't really have good effective evaluations of the incidences and effectiveness of existing programs.

However, someone has calculated that for another component of the nutrition question, which is a child with a nutritional defect due to a genetic defect which can be remedied by nutritional intervention. The savings to the taxpayers from the existing program fully implemented would be on the order of a couple billion dollars, I think \$1.8, or something like that.

Now, of course, these children represent the tip of the iceberg. These are the children that are much more easily recognized. We have in addition, the severely malnourished children really determined to be at risk.

When we progress to other factors such as borderline obesity, borderline anemia, borderline low birth weight, we have a more difficult time coming up with good figures. There have been attempts in the past to calculate some of the cost-benefit ratios to this and I remember that President Nixon in his 1969 address to the White House Conference on Food and Nutrition estimated that it cost \$100 in remedial care for every \$1 we fail to spend on nutrition programs for children.

There is a recent estimate from Texas in terms as that 8 percent of the incidence of low birth weight in that State, and it's quite large, is due to or could be remedied by nutritional intervention programs.

As you well know, the hospital district that is serving your constituency has an incidence of low birth weight that runs something like 23 percent of all births, whereas the private hospitals in our city only run 4 percent. It's probable that the difference of 20 percent could be impacted by nutritional intervening programs during pregnancy.

Mr. LELAND. Can you tell us about the new research in the areas of digestive diseases, particularly the treatment of acrodermatitis enteropathica or about the use of total parental nutrition?

Dr. NICHOLS. I would like to speak to the question of digestive diseases, but not to any great detail on the enteropathica. It's a disease associated with an inability to absorb dietary zinc and is cured by large oral doses of zinc, but the major gastrointestinal disorder in this country is not cancer of the colon, today it's gastroenteritis in infants, and as we all know, the fifth ward is full of infantile gastroenteritis. Our major form of malnutrition in the Harris County Hospital district is in the child who has had repeated attacks of gastroenteritis and who enters the hospital with severe atrophy of the gastrointestinal track and requires 3 months of parental nutrition before we can rehabilitate him.

That requires a tremendous expenditure, on the order of \$350 a day for 3 months in order to rehabilitate that child.

I think this emphasizes the very important interrelation between nutrition and infection. The major cause of severe malnutrition in our population is infection and the major cause of reduced immunity in our population is malnutrition. It's a synergistic effect and

this emphasizes the reason why health and nutrition have to go together.

In 1932, the professor of agriculture at Aberdeen, Lord Carr, spoke to the League of Nations. He said there will be a day when agriculture and health are no longer separated and, gentlemen, I think this bill helps speed that day.

Mr. LELAND. You are wonderful.

Mr. WAXMAN. We have a call to the House floor to respond to a vote.

We are going to have to break right now, vote, and come right back.

[Brief recess.]

Mr. LELAND [presiding]. We will resume now.

The chairman has turned the gavel over to me. So we will continue and finish up with our last panel. The CHAP legislation has a requirement to provide nutrition counseling. How would the long-term objectives of my companion bill enhance this work?

You have alluded to the enhancement in your earlier statements. I would appreciate it if you can expound a little bit more on how my legislation can increase child health.

Dr. NICHOLS. I think it is essential that nutrition be seen in the context of health. One of the difficulties has been that other forms of nutrition education, particularly as it relates to the pregnant and lactating woman and the infant have had administrative guidelines that have limited the breadth with which they could approach the problem.

I believe we should not take away any education resources available through other agencies and other departments, but I think we should add it in a way that coordinates the total health care supervision of the population that needs health education most.

I think there is some particular area where this is demonstrated in a very significant way. Human lactation requires much closer supervision, particularly in one high risk candidates who have not had personal experience and whose mothers have not had personal experience with human lactation. Yet I think an objective to establish human lactation in these high risk areas of our population is very important. There is evidence that the evidence of gastroenteric infections could be cut to one-seventh of the present rate if we could introduce effective programs to encourage human lactation as a national priority.

I think it would be foolhardy to separate the lactation program away from the health care base because these children need to be supervised and the mothers need to be observed for the problems of lactation that come up, inadequate confidence, inadequate milk production, problems of cracked nipples. These need to be anticipated and the mothers guided through this from a health base as well as a nutrition base.

Mr. LELAND. Dr. Owen, would you care to comment on that?

Dr. OWEN. I will come back to that in a minute.

Dr. Nichols noted that gastroenteritis is really the most common disease of the intestine, not cancer of the colon. I would like to comment a little bit further on that in terms of some observations in a specific setting among one of the southwestern groups of native Americans.

This happened to be a group of Apache Indians in Arizona. We did a survey there in 1969. We certainly found some significant problems, both in terms of nutritional status and general health status and it was also recognized that there were some problems in the health care system, particularly in the ambulatory setting. Right after we were there in 1969, there was a group of researchers from Johns Hopkins University looking at methods of handling, on an ambulatory basis, this major problem, namely gastroenteritis.

Having returned there 7 years after our earlier survey, we resurveyed the original cohort of children and another cohort of preschool children to see what had happened in 7 years. Three interventions, that is, nutrition education, management of gastroenteritis and extension, and coordination involving both tribal initiatives and the Indian Health Service served to bring together what had been previously fragmented or nonexistent health services.

When you see a reduction in infant mortality from a figure of the order of 70 per 10,000 to something less than the average in the State of Arizona, it is, I think, clear testimony to the fact that coordinated efforts in nutrition and nutrition education in a health care setting were beneficial and effective.

I agree with Dr. Nichols that one of the benefits of the WIC program was the most effective merger of nutrition education and food assistance in a variety of different health care settings.

Mr. NICHOLS. I have a little interesting story I will tell you. There is a very interesting town south of Mexico City called Tlaltizapan.

This is a little town where Dr. Cravioto studied the ecology of health. A number of years ago they were following very carefully the growth of children in this community who lived in very borderline circumstances. They suddenly noticed an improvement of the development of the children in this village. They were growing better; they were performing better on psychological tests. The investigators went back over their data and tried to analyze it and determine what was the vector that made this impact. They were really very perplexed concerning the origin of the change in health.

There was very great soul-searching and very careful scrutiny of what was happening in the village. They found that the families, as poor as they are, have transistor radios and there was a very catchy jingle on the transistor radio selling a soap. It said, "Wash your hands with Lifebuoy" or something equivalent to that in Spanish. The families had begun to wash their hands and the act was traced to a reduction in infectious disease in the infants and consequently improved child health performance.

I raise this to show you the relationship between child health and infection and how media can have an impact on health. I believe that this supports the bill you have proposed.

Dr. OWEN. In that regard I commented in my written testimony that maybe half of the States are involved in the CDC nutrition surveillance and most of the efforts are directed at the high-risk/low-income segment of the population. I think that is appropriate priority as a start. When we look at this experience and many others in the Third World we realize that if our educational efforts, particularly in terms of mass media, are only going to be focused at

the high-risk/low-income segments of the population rather than at the population at large, such educational efforts are doomed to failure.

Would you agree or disagree?

Dr. NICHOLS. I would like to expand one other concept about the bill Mr. Leland has proposed. I was once on a panel with Margaret Mead. She said the problem with trying to get overseas people to lactate is that nobody does it in the United States. That is not exactly true; it is turning around, but I think there is a principle here. If we can coordinate and provide good child health care in the United States, our positive statement in this regard is going to be important to the world as we continue to provide, by default, if not by intent, leadership to the world's health care system.

Mr. LELAND. The statement you make is incredible. I hope that we can provide that leadership.

This is a box of Trix, as you well see. On it they have a special message to parents. It gives some nutritional information or at least purportedly so. Claimed therein is that it is a highly fortified cereal, fortified with 8 to 10 minerals and vitamins which, by the way, contains one-third sugar. Is this more nutritious than a more traditional breakfast?

This bothers me a little bit. I am somewhat confused about this type of statement, more of x, y, and z is better. Does fortified mean that the food is more nutritious?

Dr. OWEN. I don't eat that particular cereal.

Mr. LELAND. Is there any particular reason why you do not?

Dr. OWEN. Well, there are some other ready-to-eat cereals that I have eaten since I was a child and I have sort of stuck with them.

This is a very, very difficult area with which to deal. This convenient form of nutrition in its native state is a very good source of protein but because of processing various micronutrients which would ordinarily be present in the grain have been lost to a variable extent. As a consequence, this cereal grain product has then been fortified to some arbitrary level with the addition of nutrients with this fortification and what is naturally present in a usual serving of cereal grain product and in milk add up to a total which is between a third and a half of what we judge on the basis of available information to be reasonable for a 1-day intake.

It generally tastes good and one could argue that it might be better in the long run for health than eating two fried eggs. On the other hand we don't have a profoundly good body of knowledge to arrive at firm conclusions that one or two eggs, fried or otherwise prepared, is necessarily bad.

We know that cereal and milk is a good source of protein and other nutrients. There is some cleverness in playing on uncertainties that people have about the propriety of eating an egg or a strip of bacon. In a way, I think it is an unfortunate form of advertising.

I don't think people buy that product or similar products because of nutrient composition, natural or otherwise. I think those items are purchased because children are exposed to advertising.

Mr. LELAND. Children are exposed to very clever advertising on TV and see the rabbit and all the antics.

Dr. OWEN. Plus the inserts in some of the packages.

On the other hand, from a nutritional point of view it is a reasonable source when consumed with milk, of essentially one-third of the USDA's variety of essential nutrients. It is not bad nutrition.

Mr. LELAND. What about the sugar content? I understand that about 10 grams of sugar are present per ounce of cereal. Can you say something about that?

Dr. OWEN. Is this a generic term that applies to both added sucrose or fructose or is this also the amount of more complex sugars present in starch, et cetera?

That is no more sugar than is present in a glass of orange juice or some comparable amount of some other food which, of course, is another way in which advertising is done on a comparative basis.

I think the right answer is that there is really no such thing as a good food or as a bad food categorically.

There certainly are some foods that are better than others.

Mr. LELAND. That is interesting. I once tried to ban the advertising of any kind of food and drug combination to children in the State of Texas. Of course, we ran into problems with Federal interstate laws.

I am now in a position where perhaps I can implement such ideas, although I doubt very seriously that I can achieve such ends.

Dr. OWEN. I think we are getting closer to a sense of responsibility in this area but I hope we don't in the process of such considerations destroy our basic system. Yet I would hope that some rational reason and agreement in terms of what constitutes acceptable, appropriate advertising and merchandising could be arrived at.

I don't know how far away we are from achieving that.

Mr. LELAND. This is somewhat beyond the scope of our perview of involvement today, but you know it is just a very serious and very critical question in my mind that is the targeted advertising to kids. I wonder what kind of judgment they can really render.

These companies impose so much leverage on parents to buy all of those things that are advertised, I think that the advertising agencies on Madison Avenue and wherever, have really done a disservice to the people, to the children in particular.

Mr. NICHOLS. I remember a few months ago you were in Houston and we had a meeting of the Senate Seven Group and you came over and gave a talk. A fellow from Turkey stood up and wondered why you didn't run all those Iranian students out of the country and your answer was they had their constitutional rights.

I am concerned about the constitutional rights that would be infringed if we got too far in this direction. I think the best approach is a positive statement of what is good nutrition.

I think that is why the media approach that you have suggested of providing positive statements has a lot more value than going around trying to suppress every little brush fire that might arise.

I think that the approach as outlined here in your bill, of a positive statement of good nutritional practice will go much further than attempts to regulate areas that are getting into constitutional problems.

Mr. LELAND. You just answered my next question.

Dr. OWEN. If you can't lick them, join them.

Dr. NICHOLS. Or do it better.

Mr. LELAND. That is precisely what Jerry has just asked me to ask you, as a matter of fact. Whether we can combat what these individuals are doing with positive and constructive means.

I am going to ask a few more questions for the record. We need to finish up because I will have to go and vote.

I will give you these questions that I have remaining and ask you if you will, if you have time, to submit your responses in writing.

I think you have seen most of them.

Dr. Oakley from the Center for Disease Control last week said alcohol consumption by pregnant women is the single greatest factor in the development of genetic or birth defects. Is this because alcohol consumption leads to a lower dietary intake or does it have its own deleterious effect?

Dr. NICHOLS. I believe Dr. Oakley must be misquoted there because I don't know of any evidence that alcohol leads to genetic disorders.

I will say it contributes to fetal malnutrition because it does two things: It supplants adequate nutrient intake by the alcoholic mother, and, second, it has clear effects on the metabolism of the nutrients within her body and the availability of key nutrients such as riboflavin to the growing infant. So it has several effects. Rather than genetic disorders, I think she must mean congenital disorders.

Dr. OWEN. I would agree with that. Unfortunately, the studies done in pregnant animals have been done with an otherwise adequate diet. As far as the congenital defects that are present in the infant, they have not been shown to be produced by deficiencies of selected nutrients. There is no question that the potential exists itself in the alcoholic woman to also have an inadequate diet.

But the expression of defects in the baby is probably not related to the nutrients.

Dr. NICHOLS. Wouldn't you agree with me that alcoholism is the main cause of malnutrition in the United States?

Dr. OWEN. Yes.

Dr. NICHOLS. I think this is a subset of that problem.

Mr. LELAND. I am going to have to run.

Dr. OWEN. We would certainly be willing to respond with written comments to any additional questions that you may have.

Mr. LELAND. We really appreciate your coming and working with us. I hope that we will be able to make some impact on our colleagues here. I have a feeling that some will be quite sensitive; some of the questions, as a matter of fact, were very relative to the interests of some of the members of the committee so that we can try to gain some support for the legislation H.R. 4362 and illuminate its direct relationship to the CHAP legislation and my interests. I personally appreciate what you have done to help us. You have been wonderful. I am glad that I am sitting in this chair in that I can say that, as chairman of this subcommittee at this moment in history.

I will ask you too, if you will, to submit your responses to the questions that we have left here. I appreciate this and we will enter those questions as a matter of record.

This committee will stand adjourned.

[The following statements were received for the record:]

American Public Health Association
Comments on
CHILD HEALTH ASSURANCE ACT
June, 1979

The American Public Health Association has previously gone on record in strong support for the need for an expanded and revised program of child health services (Testimony of C. Arden Miller, M.D., APHA, August 8 and 9, 1977, Subcommittee on Health and Environment, Committee on Interstate and Foreign Commerce).

We again wish to emphasize the need for Child Health Assurance Act legislation currently under consideration by this subcommittee.

APHA strongly favors extension of eligibility for the program to cover as many children and women during pregnancy as possible. Although we would not diminish the emphasis which is placed by this legislation on pre-school children, mandatory coverage should be extended to age 21. The potential health benefits of such a program to adolescents and teens needs to be fully realized.

We favor facilitating the participation of multi-provider systems, especially those associated with state and local health departments, the special projects of Title V and other public provider systems. In areas of provider shortage, we urge the allocation of resources to help develop and expand such systems.

This Association further believes that there must be a definition of acceptable outcomes achieved under CHAP, resource allocation to help facilitate the achievement of desired outcomes, and appropriate penalties which do not work to the disadvantage of clients and services.

The future of mothers, infants and children seems especially urgent in light of the uncertain future of National Health Insurance and the often limited coverage specified in current proposals. We hope Congress will work quickly to enact this urgently needed legislation.



AMERICAN HOSPITAL ASSOCIATION

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WASHINGTON OFFICE

STATEMENT OF THE AMERICAN HOSPITAL ASSOCIATION
ON H.R.2159, H.R.2461, AND H.R.4053, THE CHILD HEALTH ASSURANCE ACT
OF 1979
BEFORE THE SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
OF THE
HOUSE COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE

June 25, 1979

The American Hospital Association, which represents over 6,100 member hospitals and health care institutions, as well as more than 30,000 personal members, appreciates this opportunity to present its views on legislation to establish a program designed to meet children's health needs.

The three Child Health Assurance Program (CHAP) proposals before the Subcommittee (H.R.2159, introduced by Rep. Tim Lee Carter; H.R.2461, introduced by Rep. Andrew Maguire; and H.R.4053, introduced by Rep. Henry Waxman on behalf of the Administration) seek to improve the health status of over 12 million children whose families or guardians have low incomes by providing for a program of regular health assessments and follow-up treatment. The AHA wholeheartedly supports such efforts to encourage preventive care and early medical intervention on behalf of children.

Hospitals have made significant efforts to provide primary care through the expansion of outpatient and ambulatory clinic programs. In addition, the AHA has expressed its support for other legislative programs which would narrow the gaps in health insurance coverage for low income groups through the standardization of eligibility and benefits under the Medicaid program. Efforts to improve access to comprehensive diagnostic and treatment services for low-income children are consonant with our policies and goals.

CABLE ADDRESS, AMERHOSP

We believe, however, that any program to improve the health of children should consider the full range of issues which will confront the patients and providers involved. Previous federal legislative activities to improve child health have been hampered by difficulties in implementation which have frustrated the original intent of such efforts. Some of these difficulties include:

- in terms of program jurisdictions, fragmentation of and conflict among different levels of related governmental, as well as private, agencies;
- failure to provide sufficient financial incentives to encourage provider participation in federal programs;
- failure to target specific populations; and
- lack of adequate data collection for program assessment.

In the context of our concern for addressing the full spectrum of these and other issues, we would like to offer the following specific comments and recommendations.

PROGRAM CONCERNS

Eligibility

Criticism of the existing Medicaid program has been directed to the fact that significant numbers of economically disadvantaged persons have been left without adequate health care services due to the uneven eligibility and varying benefit packages of the states. Among the most disadvantaged are children, for whom proper diagnosis of adolescent conditions, dental care, immunizations, nutritional counseling, and health education could prevent a substantial amount of chronic and debilitating disease in later life. We support the intent of each of the proposals to standardize eligibility requirements among the states so that children of intact families, as well as of single parent households, would be covered under the program.

The AHA urges the Subcommittee to adopt the income standards for eligibility contained in H.R.2461, which will bring the benefits of basic medical services to the greatest number of children. The extra costs associated with broader eligibility

will, we believe, be returned manyfold in the savings from reductions in hospitalization, chronic medical care, and lost work time in future years.

Comprehensive Services

The AHA strongly supports the screening of eligible children in settings which provide a full range of comprehensive diagnostic services. Such settings should also provide for necessary treatment in a timely manner, since screening programs are of little value unless timely follow-up care is assured. We feel the overall approach of H.R.2159 and H.R.2461 is preferable to that of H.R.4053: the former two bills, in contrast to the latter measure, require state plans to assure the availability of appropriate support services and place a primary responsibility on all CHAP providers to (1) assure necessary corrective treatment, (2) take case management responsibility for assessed individuals, and (3) assure continuing accessibility to participants. Assurances of timely and continuous treatment reduce the need for more expensive modes of medical care which may become necessary when medical conditions reach an emergent or acute stage. We believe this to be one important means of controlling medical care costs over the long run.

We realize, however, that not all health care providers have the full range of diagnostic and treatment services in a comprehensive health center. This is particularly true in sparsely populated rural areas. In such circumstances, it is appropriate that local public agencies assist providers in the accomplishment of follow-up activities. It is logical that community agencies will be able to perform this function effectively since they generally possess more detailed knowledge of their service areas than state agencies. We therefore support the language of H.R.2461, which would allow participating providers to furnish information necessary for follow-up actions to local public or nonprofit community health agencies, as well as the designated state agencies.

Finally, in regard to comprehensive services, we are deeply concerned that none of the bills specifically includes hospitals within the definition of "provider." As we indicated at the outset, many hospitals have well organized outpatient departments and clinical programs designed to provide primary care services to their communities. Indeed, in urban areas, where the shortage of private physicians has become especially acute, hospital outpatient departments are often the only source of continuing primary care. Since our common goal is to develop a more rational system of health care in this country, there should be no question as to the eligibility of this major segment of primary care providers to participate in the program.

Prenatal and Postnatal Care

The success of any program to improve child health will depend greatly upon the adequacy of efforts to ensure proper prenatal and postnatal care for low income expectant mothers. By including screening and appropriate follow-up care for expectant mothers in this program, Congress will be taking necessary steps toward the goal of improving the health status of children and reducing further the nation's infant mortality rate.

Studies have shown that many environmental and social factors, such as poor housing and the lack of proper nutrition, prevalent among the low income population, are directly linked to a high incidence of physical and mental disabilities in infants. In addition, the frequency of alcoholism and drug abuse in low income groups makes it imperative that expectant mothers be screened so that high risk pregnancies can be promptly identified. The identification and treatment of high risk pregnancies is a priority concern of many hospitals, physicians, and health planners. We believe the CHAP approach to be well suited to the alleviation of these concerns.

We therefore support the expanded coverage of low income pregnant women for basic Medicaid services proposed in all three bills. AHA also supports the provision in the bills that will help reduce infant deaths and disability by providing coverage for infants at birth, in contrast to some current state Medicaid programs that begin coverage at six months of age.

Dental Care

The AHA believes that adequate dental care is an important component of a child health program. The problem of dental neglect, and its long-term consequences, cannot be overestimated. We firmly support the intention of these proposals to include dental care for children in a manner comparable to other medical services under the Medicaid program.

Health Education

Health education strategies should be an integral part of the CHAP approach. Since public awareness will be an essential element of the program's success, we suggest that the proposals be expanded to provide funds for both national and local promotion of public health education. In addition to traditional health education functions, this activity also could reduce the burden on provider resources by instructing parents on the appropriate use of services.

The health education strategies should target information to both the parent and the child. It is important that the parents receive information relating to the child's growth, development, and health care, in order to provide a more healthy environment for the child. Moreover, facts should be made available to assist the child in making sound health decisions, thereby reducing dependency on the system.

An excellent time to provide appropriate health education information is during the periodic screening of the child. Incremental education models could be designed for implementation by a number of different health professionals. In addition, health

education should also be a part of any continuing medical care that is provided.

Hospitals have traditionally conducted inpatient education activities. With increased community emphasis on outpatient and preventive care programs, a large number of institutions have extended their educational programs beyond the hospital, with the result that a substantial capability in program design and administration now exists in community hospitals. It is appropriate that these health education activities, as well as those traditionally provided by governmental and voluntary health agencies, be integrated into the comprehensive services provided under CHAP.

Immunization Efforts

All three proposals before the Subcommittee would create a national child immunization effort by including immunizations among the required assessment services. We believe this effort to be important and worthy of congressional support. However, we would point out that the immunization program may be jeopardized by its failure to provide patients and providers with adequate indemnification for vaccine-associated injury. Such injury is a predictable risk of any widespread vaccination effort. In light of the serious economic and legal implications of malpractice actions, providers may require assurance of indemnification as a condition of participation in the program.

Regulatory Authority

All the proposed CHAP bills would grant significant rulemaking authority to the Secretary of HEW for the implementation of the program. This authority pertains to, among other things, the specific terms of the child health assessments and the definition of other required services. AHA believes that it is essential that the Secretary seek broad input from providers, including hospitals, in the development of these regulations. Without careful consideration of the effect of the programs on other provider responsibilities, some provider disincentives may be created.

For example, if the assessment period is too long, providers may be discouraged from performing other primary care services, such as school or summer camp medical reports for their CHAP patients. If the provider relies on dated assessment information, malpractice liability could arise if a new disease or injury is subsequently discovered. On the other hand, if the provider performs a new assessment for these purposes, reimbursement may be denied, since the examination would not be "timely" in accordance with the regulations. To avoid such situations, we urge the Subcommittee to direct the Secretary to consult with provider groups prior to the publication of proposed rules for the program.

ADMINISTRATIVE CONCERNS

Financing and Payment System--Provider Incentives

Experience with the financing and payment system utilized by the Medicaid program is of serious concern to hospitals. While the entitlement to health benefits for low income individuals has resulted in their access to needed health services, the unevenness of eligibility requirements and variations in payment methodologies among the states often have led to failure of the program to meet the full costs of providing high quality care.

The existing Medicaid program permits some states to pay less than the full costs incurred in rendering services. As a consequence of Medicaid rate freezes, benefit limitations, and partial payments under some state plans, other hospital patients and third-party payers have, in effect, subsidized the costs of services rendered to Medicaid beneficiaries. Such inequitable circumstances could make it difficult for providers to participate in CHAP. We would like to point out that it has long been a policy of both providers and the government to avoid a "two-tiered" health delivery system, which may result if a significant number of providers are discouraged from serving the beneficiaries.

Moreover, we strongly support the state plan requirement of H.R.2461 which specifies that agreements with providers must include "terms of prompt payment and high reimbursement."

Moreover, the method of payment must recognize the full costs actually incurred by these Medicaid patients. Arbitrary fee schedules, which are commonly used by the states under some Medicaid programs, do not assure providers that their full costs will be met as increases in demand and changes in the costs of resources (including new technology) occur. We recommend that agreements with providers specify that the full reasonable costs of services provided for program beneficiaries be paid.

Increased demand for pediatric services will inevitably result from a broad screening effort. It has been estimated that only about one-sixth of the over 12 million children eligible for screening services under the current early periodic screening and diagnostic treatment program actually have been screened. The increased case load under a new and expanded program would come from three sources: (1) patients not previously eligible for, or taking part in, the existing screening program; (2) patients referred to qualified providers with the necessary diagnostic and treatment services to meet medical care needs; and (3) the provision of additional services to current participants as a result of more thorough and comprehensive screening and follow-up requirements.

Although the long-run effect of screening and treatment programs may be a net decrease in pediatric inpatient utilization, it must be recognized that an increase in inpatient volume will also occur from two sources: (1) the treatment in the hospital of serious conditions discovered in the initial screening of program participants; and (2) a demand for follow-up diagnostic and corrective procedures which can only be performed on an inpatient basis. While the former component can be expected to diminish over time, the latter cannot.

We are pleased to note that the bills recognize the need to provide adequate financial resources for the program by authorizing an increase in the federal matching rate for CHAP services. These additional resources will help the states address the demand and payment issues which will also affect provider participation.

In this regard, we believe the approach of H.R.2461 to be the most effective. It would authorize a federal matching rate of 90 percent of expenditures for outpatient services under the program. The other proposals would add percentage points to existing state assistance levels. However, in those states in which Medicaid reimbursement is already seriously inadequate, the addition of four to twenty-five percentage points to the state matching level may not be sufficient to meet the increased number of eligible children. Experience has shown that when state resources are limited, benefits are maintained at the expense of provider reimbursement levels. Many providers may not choose to participate if it is perceived that state resources will be inadequate to meet the costs of providing the increased volume of services.

In order to encourage support from those providers offering comprehensive services, there must also be assurances that the additional costs attributable to the inpatient component will be adequately reimbursed. For this reason, we urge the Subcommittee to provide an appropriate amount of additional federal matching for inpatient services under this program. We strongly support the intent of H.R.2461, which specifically provides an increase of 10 percentage points in the federal medical assistance level (up to 90 percent) for amounts expended for necessary inpatient services under CHAP.

As we noted in our discussion of outpatient service reimbursement above, however, this incremental approach may not be sufficient in states with already low reimbursement levels. The incremental approach may result in uneven treatment, and therefore uneven participation, of providers in different states. We therefore urge the

Subcommittee to consider the alternative of establishing a uniform federal matching level for inpatient CHAP services. We believe that the level of assistance must adequately reflect the need in all states to meet the costs of inpatient care provided as a result of the assessment program.

All three proposals would provide 75 percent matching for the costs of outreach services. We believe this to be an important provision and wholeheartedly support its inclusion in the legislation. Especially in rural settings, outreach programs (in which providers or community agencies take the initiative in making contact with the patient) are frequently the only means of assuring that these populations are served. We believe that outreach activities should be a required component of state CHAP plans and we specifically support the language of H.R.2461 which emphasizes the use of community-based nonprofit organizations for this purpose. As we noted earlier in this statement, we believe the familiarity of local institutions with their service area will assure more effective outreach services.

Finally, based on our foregoing comments, the AHA is also pleased to note that both H.R.2159 and H.R.2461 require the Secretary of HEW to study provider participation in CHAP and methods for improving that participation. We believe both providers and program beneficiaries will benefit greatly from such a study.

Allied Health Professionals

In order to encourage efficient and economical provision of services under the program, the AHA believes that the legislation should specifically recognize the role that the nurse practitioners and physician extenders can play in some screening and follow-up activities. We suggest that the state plans encourage, to the extent permissible under state law, the participation of allied health personnel in CHAP.

Coordination with Other Programs

A number of programs receiving federal support provide related services for children, among them various health, nutrition, and social services. The AHA believes that the legislation should provide for the administrative and clinical coordination of CHAP and other federal programs for the provision of health and related social services to children. Such coordination would measurably increase the combined impact of the services on the target population and decrease administrative costs.

To that end, we support the provisions of H.R.2159 and H.R.2461 which require the states to assure such coordination and require the Secretary of HEW to report to the Congress on the coordination of CHAP, Medicaid, the maternal and child health programs, and other federal programs.

* * * * *

We appreciate the opportunity to present our views on these CHAP proposals, whose intent we support. We will be pleased to provide any additional information or assistance the Subcommittee requests.

STATEMENT OF THE
AMERICAN OPTOMETRIC ASSOCIATION
ON
CHILD HEALTH ASSESSMENT
(H.R. 2159, 2461, & 4053)
TO THE
SUBCOMMITTEE ON HEALTH
AND ENVIRONMENT
OF THE
COMMITTEE ON INTERSTATE
AND FOREIGN COMMERCE
UNITED STATES
HOUSE OF REPRESENTATIVES

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961-03

June 15, 1979

The American Optometric Association appreciates this opportunity to submit comments on the specific proposals (H.R. 2159, H.R. 2461, H.R. 4053) that have been introduced to improve the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program.

We enthusiastically endorse the concept, which is contained in these measures, that EPSDT must do a more effective job in providing screening and then in fostering the provision of needed diagnostic and treatment services. One criticism that our members frequently make of EPSDT is that it has only superficially reached out and affected the health status of its beneficiaries. Although each person must in the end make his or her own choice as to whether to seek health care, this program does have the potential of raising the health consciousness and health status and thus the quality of life and work of children from economically disadvantaged backgrounds.

However, our one concern centers around another problem area which our members sometimes relate to this association. That area is the central issue of program accessibility to the provider; here, specifically, the practical ability of optometrists to see patients who have been screened and found to have suspected vision problems.

Contributing to this concern is inadequate screening criteria. We addressed this specific point in our statement on child health which we submitted to the subcommittee on May 21, 1979.

Of equal importance to this concern is the referral mechanism from screening to diagnosis and treatment. Today, referrals

under EPSDT are typically made by screening organizations and providers. Despite existing federal and state laws which assure freedom-of-choice of an optometrist or a physician skilled in diseases of the eye on the part of the beneficiary, the state optometric associations note "the problem of referrals due to medical domination of the program" as per a recent questionnaire on federal programs involvement. This problem effectively limits, in some areas of the country, the availability to EPSDT eligibles of two-thirds of the potential pool of vision care providers, the optometrists. It also prompts the unwillingness of many optometrists to have anything to do with EPSDT.

The impact of this problem is underscored by the fact that 76% of optometrists do accept patients under the Medicaid program as a whole; whereas, only about 50% of physicians accept Medicaid patients. Indeed, these statistics emphasize the willingness of optometrists to see Medicaid patients, even at a reduced fee -- if the referral mechanism permits this to happen.

Given this problem, we must raise the question of the impact of adding a "coordination of care" requirement to an improved EPSDT program. Will such a requirement further reduce the practical ability of persons who enter the Medicaid delivery system through screening, rather than through direct appointment with a health professional for examination, diagnosis and treatment, to be seen by a nonmedical practitioner? Will

such a requirement have the effect of reducing the pool of providers available for diagnostic and treatment services?

To solve this problem, we would recommend the addition of language pertaining to referrals in the bill which the subcommittee reports. The language would require each screening provider to make referrals in a manner without prejudice to any health discipline that is licensed to provide a service. Current law guarantees freedom-of-choice on the part of the beneficiary; such new language would extend this requirement to the referral source.

Our recommendation is designed to assure maximum provider acceptance and participation. We respectfully urge its adoption.

STATEMENT
of the
AMERICAN MEDICAL ASSOCIATION
to the

Subcommittee on Health and Environment
Interstate and Foreign Commerce Committee
United States House of Representatives

Re: HR 2159, HR 2401 and HR 4053 - The
"Child Health Assurance Act of 1979"

June 13, 1979

The American Medical Association takes this opportunity to submit its views on the above described legislation that would increase the number of children and pregnant women eligible for Medicaid and replace the current Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program under the Social Security Act.

Background on the Proposed Legislation

This proposed legislation would amend Title XIX (Medicaid) of the Social Security Act to provide for a Child Health Assessment Program. By these changes, many children in low income families, who are ineligible currently for Medicaid because they are members of intact families, would come under Medicaid. In addition, eligibility for Medicaid would be extended to cover pregnant women with low incomes who do not presently qualify because they do not have a dependent child living with them.

Children covered by the CHAP provisions would be persons under the age of 18 (and States could elect to include children between 18 and 21). They would be entitled under Medicaid to periodic health assessments and a broad

range of health services. Pregnant women covered under the extended Medicaid provisions would be entitled under Medicaid to care and services during pregnancy and for 60 days following the termination of pregnancy.

For children, mandatory services (that is, services that a State must provide under Medicaid) would include, in addition to hospital and physician services and skilled nursing care, services such as routine dental care and vision and hearing services. Moreover, services other than mental health care and dental care could not be limited as to amount, duration or scope.

CHAP services could be provided by a variety of providers, among them: physicians; community health centers and migrant health centers; projects funded by Title V; Indian Health Service facilities; State and local government health departments; and schools.

In advance of performing services under CHAP, a provider would have to become an eligible participant. This would entail entering into a written agreement with the State agency responsible for administering Medicaid whereby the provider would agree to provide to eligible children services including periodic health assessments, diagnostic and treatment services to those assessed, and, when indicated, referral to appropriate providers for needed treatment.

The three bills before this Subcommittee also include, with variation, provision for agreement whereby the provider would undertake patient follow-up to ensure the provision of services for which a referral has been made. One of the measures allows, as an alternative, that the provider furnish follow-up information to the appropriate State agency. Others simply authorize the State to include such an alternative in the terms of agreements.

A further element in the written agreement provides for assumption by the provider of responsibility for the management of the medical care of each eligible individual whom the provider has assessed and for assurance that the child health assessments are performed on a timely and periodic basis. This is specifically set out in HR 2159 and HR 2461, and appears with variation in HR 4053. HR 4053 creates a class of providers designated as "continuing care" providers. Only the "continuing care" provider would assume the responsibility for the management of the medical care of the assessed child.

Payments to a State for services of "continuing care" providers would be made in accordance with methods and standards prescribed by the Secretary. Under this authority, the Secretary could set minimum reimbursement levels (nationally or by area) and could permit or require payment based on a prospectively determined capitation rate with payment on a periodic basis. The Secretary would also have authority to permit or require payment incentives to "continuing care" providers.

The extent of federal reimbursement under the Medicaid program for services under CHAP would depend upon a State meeting federal levels of performance, measured in terms of informing families of the availability of CHAP services, the proportion of children who are provided assessments, the timely provision of medical care or services, and provider compliances with the terms of agreement. Two of the bills under consideration by this Subcommittee--HR 2159 and HR 2461--would impose a penalty of 20% reduction in federal matching for failure of the State to meet applicable standards of performance. Good performance under the CHAP standards would be rewarded with a 25% federal matching rate bonus.

By comparison, under HR 4053 the effectiveness of the State program would be measured under a formula which is based on assessments, care and treatment provided to children, with added weight being given to children who received the services under agreements with "continuing care" providers. Applying the formula, the State's federal medical assistance percentage otherwise determined under the Medicaid law could be reduced by as much as five percentage points or increased by as much as 20 percentage points (to a maximum of 90%).

Comments

The Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program that is presently in effect was designed to respond to health care needs of children by affording them access to health assessments and care and treatment for conditions that were diagnosed in such assessments. Approximately 22% of the children screened under EPSDT and found to need treatment do not receive the services required. It is clear that there must be more attention paid to the need for follow-up care. Improvement in EPSDT is surely needed if the program is to meet its objectives.

The legislation before the Committee would replace EPSDT, however. It seeks to meet the objectives of EPSDT by changes in the Medicaid law; and in doing so would establish within Medicaid, for one group of beneficiaries, a special set of benefits, a special definition of providers and conditions of provider participation, special rules of Medicaid payment to providers and federal payments to States. The legislation proposes, in effect, a national health insurance program for a segment of the population and would incorporate this program in Medicaid.

There appears to be no clear understanding of the reasons for the failure of EPSDT, and no base of experience as to what effect the proposed changes might have on Medicaid and the provision of care for the children. We know of no well-conducted studies that establish any guidelines for program development. This legislation would introduce a new program, with distinctive needs and copious administrative requirements, in a Medicaid program already beset with complex problems.

In assessing the shortcomings of EPSDT, it should be remembered that that program is even now being administered through Medicaid. We should not now be rushing into a broadly expanded Medicaid involvement before added study and better understanding can be combined to recognize and meet the problems. There are weaknesses in the present EPSDT program, but that program is fulfilling a needed service and deserves continued support. Modification of EPSDT to address identified problems would be appropriate. The shortcomings of EPSDT should not be addressed through a major restructuring of Medicaid, in the face of the magnitude of the difficulties implicit in an undertaking within Medicaid to mesh and administer two separate and distinct programs.

The Association does not believe that partial failure of a program to meet all its goals should outweigh its partial success and lead to total replacement. Rather, we feel it appropriate to build on its successes and correct its errors, instead of starting from scratch with a brand-new and untried approach.

The federal government is already deeply involved in a large number of health care programs, each addressed to a particular segment of the population in a targeted approach to meeting the health care needs of our citizens.

For example, there are two special programs devoted to assuring maternal and child health--the Maternal and Child Health Care provisions under Title V of the Social Security Act and the current EPSDT program under Title XIX of the Social Security Act. While these two programs are complementary, they are also to some extent duplicative. Each of these programs has a function that we believe should be strengthened and retained to assure quality health care to eligible children and their mothers. Neither was intended to nor can it reach all deserving potential beneficiaries. We urge that the two programs be reconsidered and viewed together in seeking an answer to the problems of reaching the children and others in need of health assessment and treatment. AMA would be pleased to cooperate with the Subcommittee in developing appropriate modifications to Title V and EPSDT.

We would like also to call attention to some of the specific features of the legislation which we view with concern.

Child health assessments under the program could be provided only by a health care provider who entered into a specific agreement with a State Medicaid agency. This provision is highly undesirable and could result in differences in the level of health care available to CHAP beneficiaries as compared to health services available to others. Requirement of the provider agreement could result in reduced provider participation, thereby narrowing the availability of CHAP services. The resultant concentration of the provision of CHAP services in a limited range of providers, for example, special "CHAP clinics," would be a disservice to CHAP beneficiaries. It would operate to restrict the medical resources available, thereby impinging on the beneficiary's right of selection of physician or other health care provider, and impact adversely on the scope and quality of care available to CHAP beneficiaries.

In entering into the agreement, a provider would undertake, as a condition of participation in CHAP, to manage the medical care of the individual to assure that all necessary medical services which are provided under the State Medicaid plan are made available in a timely manner, and to assure that reassessments are performed on a timely and periodic basis, as required by regulations of the Secretary.

While it is desirable for a patient to have a primary physician on whom that patient may rely for coordination of his medical care, we take strong exception to any specification in the law that would require the health care provider to assume responsibility for assuring that a patient received follow-up treatment. The physician-patient relationship is a voluntary one, and the physician maintains no control over whether a patient will return for follow-up treatment and/or consultation. To mandate by law that a health care provider is responsible for a patient over whom the provider has no control once the patient leaves the office or institution, is at best a gratuitous requirement incapable of fulfillment; at worst, it is a condition which may well deter physician participation in a program because of ostensible legal implications.

Adding to the discouraging aspects of the CHAP legislation, from the standpoint of physician participation, are the limitations on reimbursement for services that are built into the program. Payment for services under CHAP, as an integral part of Medicaid, would be governed by Medicaid rules and, accordingly, would be restricted in many states to insufficient levels. Under Medicaid laws, no reimbursement can exceed what Medicare would pay (already at arbitrarily set levels), and Medicaid rates of payment are generally

even lower. Retention of the artificially restricted payment levels under Medicaid will accentuate current problems facing the Medicaid program. This impediment to physician participation should be removed if the CHAP program is to provide full access by individuals to the intended benefits of the program. HR 4053 would allow the Secretary unilaterally to establish reimbursement levels. We would urge, as a statutory standard, that reasonable reimbursement be made for physician services.

Providers participating in CHAP will also have the added burden of making reports, such as the State or the Secretary might require, to assure compliance with the requirements of the program. No specific guidance is provided, however, with respect to the content of these reports nor the extent of the data that must be furnished. Reasonable bounds as to the scope of such reporting and the material to be provided should be described in the legislation. We also ask that careful consideration be given, in the development of the report requirements, to the burdensome paperwork and administrative tasks that will be created.

As we have expressed earlier, we fully support the provision of health care services as are envisioned under the present Early and Periodic Screening, Diagnosis and Treatment program. The program should be improved, but changes should be made so as not to discourage full opportunity of patients to have access to care, and should be made in conjunction with an evaluation of other related programs. We are concerned, as is the Subcommittee, with health care costs, with efficiency in health care delivery, and with the quality of health care services provided. It is with these concerns in mind that we raise these issues with respect to the creation of a new CHAP program as proposed in the legislation.

We urge that, in developing modifications of the current EPSDT program, consideration should be given to the availability of maternal and child health care under Title V of the Social Security Act. Title V, in its support of local and regional programs, has long been a prominent and effective source of health care for underserved children and youth. Established in 1935, this program currently affords health services to mothers and children who, for economic reasons, have difficulty in obtaining the services they need. The Title V program would be expanded under legislation recently developed in a joint effort of the American Medical Association, the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists, so as to address more fully the spirit and intent of that program in meeting the national needs of maternal and child care and giving added emphasis to special health service needs of prospective mothers and the developing fetus, the needs of the infant in its first year of life, and the need for treatment and counseling for conditions associated with pregnancy, venereal disease, drug addiction and mental health. A draft of the legislation is attached, and we commend it to the attention of this Subcommittee.

Conclusion

We do not believe that the CHAP program should be integrated in the present Medicaid law as proposed. The effect of such legislation is to add further confusion to an already heavy burden of administering Medicaid laws. The CHAP program is designed specifically to meet medical needs of children, and is addressed to this segment of the population, distinct from the general population that may be covered under Medicaid at the present time.

To meet these needs, the legislation sets out conditions of eligibility that are different from the rules that will govern Medicaid beneficiaries in

general. By definition, a different set of providers would be rendering services to the CHAP beneficiaries of the Medicaid program than to the other beneficiaries under that program. This would include non-medical personnel in institutions like schools who are not now authorized to perform services under Medicaid. It would also exclude some practitioners who are eligible as providers under Medicaid but are ineligible as providers under CHAP. Special rules will apply to a newly created category of "continuing care" providers who will be performing as such under CHAP only. The Secretary would be empowered to establish reimbursement levels and incentives for "continuing care" providers under the CHAP provisions of Medicaid; and this will create a paradoxical situation of a physician who is subject to variations in reimbursement under Medicaid, depending upon whether or not the Medicaid patient was covered under the CHAP provisions of the Medicaid program. The rate of federal reimbursement to a State for some CHAP services, under the proposal, could differ from the rate applicable for Medicaid services generally. Federal reimbursement to States would be subject to adjustment based on a determination by the Secretary that with respect to CHAP standards a State failed to meet a desired level of performance, in which case a penalty rate would apply, or achieved a high performance level entitling it to a bonus rate. The CHAP program is a distinctive program, and should not be imposed on the Medicaid program. Other possible alternative approaches should be explored and evaluated.

In support of the current EPSDT program, this program is fulfilling a vital need and providing certain health services to children of low income families. Yet, while we support the present EPSDT program, we believe that this program should not be viewed as addressing the total health care problems of our nation's children. As we pointed out earlier, EPSDT services are required to be provided under existing State Medicaid plans. Yet, EPSDT services have not been provided

to all eligible Medicaid beneficiaries. We suspect that many of the basic problems with the EPSDT program may not be in the scope of benefits but rather in the administration of the program. We do not believe that the broad reforms of Medicaid suggested in this proposed legislation would necessarily achieve the desired goals.

For optimal care for children within the contemplation of the legislation, the program must be attractive to providers with the necessary skills. The proposed provider agreement will not add to the quality of care and services to be performed, but will discourage provider participation that could sharply reduce access by beneficiaries to participating providers with the needed skills for performance of the highest quality of services in the implementation of the program.

We urge that the Subcommittee consider modifications consistent with our specific concerns with the proposed legislation. While we support the general concept embodied in the Child Health Assessment Program legislation, we urge that the Subcommittee not adopt this proposed legislation as it is presently constituted.

AMENDMENTS TO TITLE V OF THE SOCIAL SECURITY ACT
MATERNAL AND CHILD HEALTH CARE

Title V is presently a program to promote the health of mothers, and children and to prevent and to treat disease and disability that lead to crippling of children. The Title V program operates in large part under a federal grant program for basic services. Under the Title V program, the State assumes a wide latitude in determining how it will implement its program, and in setting program policy.

Since its inception in 1935, Title V has played an important role in providing health care and improving the health of the population it has served. In the attainment of its objectives, however, it has operated with limited funding and outside the framework of a specific organizational structure. The number of individuals and conditions eligible for coverage under Title V has, however, continued to increase.

If the program is to continue to provide services in a meaningful manner it is necessary to revamp certain portions of the Act while retaining the useful, successful, and familiar basic structure of the program.

The proposed amendments would address three basic areas: funding, organization, and intended beneficiaries.

The first significant modification would be the inclusion of program emphasis to include "women, infants, children, and adolescents." This modification makes clear that the program is intended to cover conditions of all mothers and their children.

While the present program does not now prohibit such care (and in fact in many instances state programs provide care to all eligible individuals) the expanded inclusion will remove any doubt as to the appropriateness of such coverage.

A second significant modification pertains to federal funding.

Under the present law funding goes to each state on a formula basis, after a basic grant in with the states providing matching funds on a 50% to 50% basis.

One change would provide added funding. The matching funds, however, would be on a 75% Federal, 25% State basis.

.....In addition to grants to states for conducting statewide activities, funds would also be allocated for direct federal grants (a) for special projects of regional or national significance and (b) for special projects of a local nature.

.....For each of the service programs (maternal and child health, crippled children, region special programs, and (local special programs) separate appropriation authorizations are provided, thus preventing a commingling of authorized appropriations. Special appropriation authorization would also be given to programs for training and for research.

.....In order to assure broadest distribution for special project funds intended as "seed" money, special project grants would have annual dollar limitations on each project.

The third significant modification pertains to organization of the Title V program.

.....A National Office of Maternal and Child Health would be established in HEW, and would monitor Title V operations in the respective states in order to determine the effectiveness of state programs.

The Office would develop guidelines to assist in the development of state plans, develop an organized system of data collection and retrieval to serve national, state, and local areas, provide technical assistance to states, and develop a long-range Title V program.

Annual state reports to the National Office would be required to identify health needs and available resources in the state, unmet needs to be addressed, and outcomes resulting from the provision of services under the program.

.....A National Advisory Committee of 15 members, including eight practicing professionals to be appointed by the Secretary, would advise and assist the National Office in program administration, policy and regulations, and would make recommendations for implementation of long-range Title V program. This committee would go into operation upon completion of the activities of the Select Panel for the Promotion of Child Health established by P.L. 96-626.

.....On the state level each state would continue to operate its Title V program.

However, under revised conditions for plan approval, the state Governor would appoint a 9-member State Advisory Council on Maternal and Child Health, a majority of which would be licensed practicing health professionals, to advise the state agency administering the plan in matters of policy, coordination, and identification of persons in need of care and basic care and services to be provided, taking into consideration guidelines developed by the National Office of Maternal and Child Health.

.....The State plan would utilize the services of individual practitioners (reimbursed at usual and customary levels) or other private health entities in the provision of services under Title V when such services are available in the community.

.....Each year the state agency administering the plan would submit a report to the National Office of Maternal and Child Care identifying outcomes to the services provided, and identifying health care needs in all parts of the state and unmet needs to be addressed. The state agency would also delineate problems and its approach in resolving such problems.

.....A special study on Maternal and Child Health delivery would be undertaken by the Secretary, directly or by contract, for the purposes of evaluating the effectiveness of the program, assessing the interrelationship between Title V and other titles of the Social Security Act, assessing the extent to which there are deficiencies in providing care to eligible persons, and recommending improvements in the delivery of care to shortage areas.

A report would be prepared by the Secretary and submitted by him with such recommendations as he deems appropriate to the Congress and the President, on or before April 1, 1981.

96th Congress
1st Session

Draft

Bill No. _____

IN THE (SENATE)(HOUSE) OF THE UNITED STATES

Mr. _____ of _____ introduced the following
bill which was read twice and referred to the _____
Committee

A BILL

To extend and improve Title V of the Social Security Act

Be it enacted by the Senate and House of Representatives of the
United States of America in Congress assembled,

SHORT TITLE

1 Sec. 1 This Act may be cited as "The 1979 Amendments to the
2 Maternal and Child Health and Crippled Children's Services Act."

3 FINDINGS AND DECLARATION OF PURPOSE

4 Sec 2(a) The Congress finds that--

5 (1) Each year many children suffer from the effects of
6 preventable illnesses and birth defects as a result of limited
7 availability of maternal and child health care;

8 (2) The health programs for mothers and infants in Title V
9 of the Social Security Act are the base and establish the

standards for most of the public health programs for mothers, infants, children and adolescents in the Nation; the program for crippled children in title V of the Social Security Act is the major health system for providing special services unique to children with crippling diseases; and the programs for providing comprehensive services for high-risk pregnant women and children living in underserved areas has had an important part in improving the health of those served. Consequently, programs must be revised and expanded to assure all pregnant women, infants, children and adolescents the promise of a healthy future.

(3) Steps should be taken to insure the national priority that all pregnant women and children have access to adequate health services, since -

(a) births to women under sixteen years increased 80 percent between 1960 and 1975;

(b) low birthweight infants are born to women under fifteen twice as often as those over twenty;

(c) twenty-eight percent of pregnant women begin prenatal care after the first trimester or have no care at all;

(d) low birthweight babies are more common among those who receive no care; and

(e) approximately three hundred thousand severely retarded people require total care at the average cost of \$18,000 per year per person.

1 (4) The program authorized by this title should be
2 extended and strengthened through improved organizational steps
3 and through special grants to achieve such desirable objectives as
4 providing health services for adolescents, special services
5 for the unwed pregnant teenage, for neonates born at high risk,
6 and for the coordination of health and education programs.

7 (5) In the provision of services for mothers, infants,
8 children, and adolescents, maximum use should be made of the
9 existing system of health care delivery and the participation of
10 private providers, and new community arrangements should be
11 created as needed to provide services for problems.

12 (6) Special grants should be made available on national,
13 regional, county and local bases.

14 (b) The purpose of this Act is to make health services available
15 to special groups (to pregnant women, to mothers and their infants,
16 to crippled children who have need for special services, for under-
17 served children and youth, for mothers and children who have disabling
18 diseases and disorders) who are at greater health risk and social
19 dependence, and for whom the cost of preventive care may be a
20 particular burden. Furthermore, health services, including preventive
21 services, shall be made available directly or through arrangements
22 with physicians, or other health providers and medical entities, to
23 mothers and children who, for economic reasons, have difficulty in
24 obtaining the services they need, and special grants for projects for
25 delivery of care to other identified groups of mothers and children

- 1 shall be made available.
- 2 Sec. 3. Title V of the Social Security Act as amended is
- 3 hereby further amended to read as follows:

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- "Sec. 501. Authorization of appropriations.
- "Sec. 502. Allotments to States.
- "Sec. 503. Approval of State plans.
- "Sec. 504. Payments.
- "Sec. 505. Operation of State plans.
- "Sec. 506. Special grants for projects of regional or national significance.
- "Sec. 507. Special grants for county and local projects.
- "Sec. 508. Training of personnel.
- "Sec. 509. Research projects.
- "Sec. 510. Administration.
- "Sec. 511. Definition.
- "Sec. 512. Observance of religious beliefs
- "Sec. 513. National Office of Maternal and Child Health.
- "Sec. 514. National Advisory Committee on Maternal and Child Health
- "Sec. 515. Study on maternal and child health delivery.

AUTHORIZATION OF APPROPRIATIONS

- 4 Sec. 501. (a) For the purpose of enabling each State to extend
- 5 and improve -
- 6 "(1) services for reducing infant mortality and otherwise
- 7 promoting the health of mothers, infants, children and
- 8 adolescents;
- 9 "(2) services to prevent disease and disability that
- 10 cripple children and to locate, diagnose, treat, and provide
- 11 followup services for children who have crippling conditions
- 12 or who suffer conditions which may lead to crippling;

1 "(3) services for locating and identifying mothers,
2 infants, children, adolescents, and crippled children under
3 State plans;

4 there are provided special grants to States and subdivision of
5 States for new activities to address the provision of medical
6 services for health problems; grants for training of personnel;
7 and grants for research projects related to the delivery of health
8 services for mothers, infants, children, and adolescents.

9 (b) There are authorized to be appropriated for the purposes
10 of this Act.

11 (1) For the fiscal year ending September 30, 1980, and for
12 each fiscal year thereafter, \$218,750,000 for maternal and child
13 health services, and \$93,750,000 for crippled children's services
14 for which provision is made for allotments under Sec. 502.

15 (2) For the fiscal year ending September 30, 1980, and
16 each fiscal year thereafter, \$78,125,000 for grants for projects
17 of special regional or national significance for which provision
18 is made in Section 506;

19 (3) For the fiscal year ending September 30, 1980 and for
20 each year thereafter, \$62,500,000, subject to the provision of
21 section 503(a)(10), for grants for projects of special county or
22 local significance for which provision is made in section 507;

23 (4) For the fiscal year ending September 30, 1980, and each
24 fiscal year thereafter, \$31,250,000 for training of personnel under
25 the provisions of section 508;

(5) For the fiscal year ending September 30, 1980, and each fiscal year thereafter, \$15,625,000 for research projects under the provisions in section 509.

(c) Notwithstanding the preceding provisions of this section, of the amount appropriated for any fiscal year pursuant to this section, not less than 6 percent of the amount appropriated shall be available for family planning services under projects under sections 506, 507 and 509;

ALLOTMENTS TO STATES

Sec. 502 (a) From the amounts determined to be available to States pursuant to section 501 (b) (after application of sections 501 (d)) allotments under this section shall be made on the following basis:

(1) For maternal and child health services:

(A) One-half of such amount shall be allotted by allotting to each State \$70,000 plus such part of the remainder of such one-half as the Secretary finds that the number of live births in such State bore to the total number of live births in the United States in the latest calendar year for which there are statistics.

(B) The remaining one-half of such amount shall (in addition to the allotments under paragraph (A)) be allotted to the States from time to time according to the financial need of each State for assistance in carrying out its State plan, as determined by the Secretary after taking into consideration the number of live births in such State.

1 (2) For crippled children's services:

2 (A) One-half of such amount shall be allotted by allotting to
3 each state \$70,000 and allotting the remainder of such one-half ac-
4 cording to the need of each State as determined by the Secretary
5 after taking into consideration the number of crippled children in
6 each State.

7 (B) The remaining one-half of such amount shall (in addition
8 to the allotments under paragraph (A) be allotted to the States
9 from time to time according to the financial need of each State for
10 assistance in carrying out its State plan, as determined by the
11 Secretary after taking into consideration the number of crippled
12 children in each State in need of crippled children's services and
13 the cost of furnishing such services to them.

14 (b) Within the limits of the amounts appropriated in this Act
15 for any fiscal year, there shall be allocated to each State a sum not
16 less than the sum allocated to the State for the fiscal year ending
17 September 30, 1979.

18 (c) Funds allotted to States which remain unused at the close of
19 a fiscal year shall be available to the Secretary for reallocation to
20 States in the following year for the purposes of this section on the
21 basis of demonstrated need to carry out the State plan.

22 (d) Payments to States from amounts appropriated pursuant to
23 section 501 (b)(1), and allotted pursuant to this section shall be
24 subject to matching by States pursuant to section 504.

25 (e) The Secretary shall conduct a study of the allocation formula

1 established by the section. Within two years, the Secretary shall
2 submit a report to the appropriate houses of Congress concerning the
3 most appropriate allocation of funds to the states along with such
4 recommendation for changes in the formula in order to insure the most
5 equitable distribution of funds to the states.

6 APPROVAL OF STATE PLANS

7 Sec. 503 (a) In order to be entitled to payments for allotments
8 to a State under Section 502 for maternal and child health services
9 and for crippled children's services, a State must have a State plan
10 which --

- 11 (1) provides for financial participation by the State;
- 12 (2) provides for the administration of the plan by the State
13 health agency; except that in the case of those States which on
14 July 1, 1967, provided for administration (or supervision thereof)
15 of the State plan approved under section 510 (as in effect on
16 such date) by a State agency other than the State health agency,
17 the plan of such State may be approved under this section if
18 it would meet the requirements of this subsection except for
19 provisions of administration (or supervision thereof) by such
20 other agency for the portion of the plan relating to services for
21 crippled children and, in each such case, the portion of such
22 plan which each such agency supervises, shall be regarded as a
23 separate plan for purposes of this title;
- 24 (3) provides (A) such methods of administration (including
25 methods relating to the establishment and maintenance of personnel

1 standards on a merit basis, except that the Secretary shall exercise
2 no authority with respect to the selection, tenure of office, and
3 compensation of any individual employed in accordance with such
4 methods) as are necessary for the proper and efficient operation of
5 the plan and (B) provide for the training and effective use of
6 paid subprofessional staff, with particular emphasis on the full-
7 time or part-time employment of persons of low income, as community
8 service aides, in the administration of the plan and for the use of
9 non-paid or partially paid volunteers in providing services and
10 in assisting any advisory committee established by the State
11 agency;

12 (4) (A) provides for the establishment of a State Advisory
13 Council to be appointed by the Governor of the State to advise
14 the State agency administering the plan that is approved pursuant
15 to subsection (b) of this section in matters of policy, con-
16 solidation of health care programs in the State, identification
17 of mothers and children in need of care, and bringing care
18 to them, and

19 (B) provides that the composition of the State Advisory
20 Council shall consist of 9 members at least four of whom are
21 practicing doctors of medicine, one of whom is a doctor of osteopathy,
22 one of whom is a doctor of dentistry, all duly licensed by the State
23 and recommended by appropriate professional organizations, and
24 the remainder of whom are members of the general public qualified by
25 education, experience or knowledge to serve on the Council.

1 (5) provides that the State agency will make such reports,
2 in such form and containing such information, as the Secretary
3 may from time to time find necessary to assure the correctness and
4 verification of such reports;

5 (6) provides for cooperation with medical, health, nursing,
6 educational, and welfare groups and organizations and, with respect
7 to the portion of the plan relating to services for crippled children,
8 with any agency in such State charged with administering State
9 laws providing for special education and vocational rehabilitation of
10 physically handicapped children;

11 (7) provides for payment of the reasonable cost of inpatient
12 hospital services provided under the plan, as determined in ac-
13 cordance with methods and standards which shall be developed by the
14 State and included in the plan, except that the reasonable cost of
15 any such services as determined under such methods and standards
16 shall not exceed the amount which would be determined under
17 section 1861(v) as the reasonable cost for such services for purposes
18 of title XVIII;

1 (8) provides, with respect to the portion of the plan relating
2 to services for crippled children, for early identification of
3 children in need of health care and services, and for health care and
4 treatment needed to correct or ameliorate defects or chronic
5 conditions discovered thereby, through provision of such periodic
6 screening or diagnostic services, and such treatment, care and other
7 measures to correct or ameliorate defects or chronic conditions as
8 may be provided in regulations of the Secretary;

9 (9) provides that when services are available in the community,
10 the State health agency shall reimburse an individual practitioner or
11 other private health entity to render the medical services;

12 (10) provides, with respect to the amounts appropriated for grants
13 for projects of special county or local significance pursuant to
14 paragraph (3) of section 501(b), that priority shall be given in
15 the award of grants to cities and counties, and other subdivisions of
16 the State for projects to be conducted in such subdivisions;

17 (11) provides for carrying out the purposes specified in
18 Section 501;

19 (12) provides for the development of demonstration services in needy
20 areas and among groups in special need;

21 (13) provides acceptance of family planning services provided
22 under the plan shall be voluntary on the part of the individual to
23 whom such services are offered and shall not be prerequisite to
24 eligibility for or the receipt of any service under the plan;

25 (14) provides --

1 (A) that the State health agency, or other appropriate
2 State medical agency shall be responsible for establishing a
3 plan, consistent with regulations prescribed by the Secretary, for
4 the review by the appropriate PSRO for the appropriateness and
5 quality of care and services furnished to recipients of services
6 under the plan and, where applicable, for providing guidance with
7 respect thereto to the other State agency referred to in paragraph
8 (2), and

9 (B) that the State and local agency utilized by the Secretary
10 for the purpose specified in the first sentence of Section 1864(a),
11 or, if such agency is not the State agency which is responsible
12 for licensing health institutions, the State agency responsible
13 for such licensing, will perform the function of determining
14 whether institutions and agencies meet the requirements for
15 participation in the program under the plan under this title;

1 "(15) provides for the development of a unified State plan
2 for mothers, infants, children, and adolescents by the maternal
3 and child health and crippled children program; the plan will:
4 describe the health care needs of the mothers and children in all
5 parts of the State and the resources available to meet such needs;
6 describe the unmet health needs of the mothers and children in all
7 parts of the State; describe the objectives and priorities as
8 determined by the State agency responsible for administering the
9 maternal and child health program and the crippled children program;
10 describe the method used by the State maternal and child health
11 program and the crippled children program to select their objectives
12 and to determine their priorities; include common goals and ob-
13 jectives for the two programs including evidence of appropriate sharing
14 of personnel in the provision of the same or similar services and of joint
15 planning concerning selected programs of common concern to both
16 programs;

1 "(16) provides that the State maternal and child health plan will
2 include the basic programs and services as determined by the State
3 advisory council taking into consideration the guidelines developed
4 by the National Office; basic programs and services will include, but
5 not be limited to, the basic health services for mothers, infants,
6 children, and adolescents, family planning, and school and health
7 programs; in addition, the maternal and child health plan will include a
8 series of special programs and projects that are conducted to meet the
9 needs of the State and to respond to the priorities in the State plan;
10 the maternal and child health plan may include such special programs
11 for mothers, infants, children, and youth as may be developed and may
12 include sudden infant death syndrome programs, dental programs,
13 expanded perinatal projects, genetic screening and counseling programs,
14 programs for unwed adolescent mothers, or other programs;

15 "(17)" provides that the State crippled children program will
16 include the basic programs and services as determined by the State
17 advisory council taking into consideration the guidelines developed by
18 the National Office; basic programs and services will include, but not
19 be limited to, programs to provide special services for handicapped
20 children; in addition, the crippled children plan will include a series
21 of special programs and projects that are conducted to meet the needs
22 of the State and respond to the priorities in the State plan; the crip-
23 pled children and youth as may be developed and may include centers to
24 provide multidisciplinary evaluation of children with severe develop-
25 mental disabilities, special programs for hemophilia, and other programs;

26 "(18) provides that special projects for maternal and infant care

1 health of school and preschool children, newborn intensive care, and
2 dental care of children being conducted within the State with funds, from
3 this title during the fiscal year ending September 30, 1978, shall,
4 consistent with the needs of the State, be maintained within the
5 State plan; and

6 "(19) provides that the State agency will submit to the Director
7 of the Office of Maternal and Child Care on or before April 1 of each
8 year, a report of the fiscal year ending September 30 immediately
9 preceding the report date that -

10 "(A) identifies the health care needs of mothers, infants,
11 children, and adolescents in all parts of the State, and
12 the resources available to meet such needs.

13 "(B) identifies the unmet health care needs of the
14 mothers, infants, children, and adolescents in all parts
15 of the State which will be addressed, respectively, by
16 State plan and by other auspices, public and private.

17 "(C) delineate problems in providing maternal and
18 child health care and priorities that will be assigned
19 by the State agency in resolving those problems,

20 "(D) describes activities to be taken under the State
21 plan for providing maternal and child health care and
22 crippled children care pursuant to this title for the first
23 fiscal year beginning after the due date of the report and

24 "(E) identifies the outcomes as a result of pro-
25 viding the services authorized by this title.

1 (b) The Secretary shall approve any plan which meets the require-
2 ments of subsection (a).

3 PAYMENTS

4 Sec. 504(a) From the sums appropriated therefor and the allot-
5 ments available under section 502, the Secretary shall pay to each
6 State which has a plan approved under this title for each quarter
7 beginning with the quarter commencing with October 1, 1979, an amount
8 equal to 75% of the total amount expended for programs pursuant to
9 the State plan, which amount shall be used exclusively for carrying
10 out such plan with respect to maternal and child health services and
11 services for crippled children.

12 (b) (1) Prior to the beginning of each quarter, the Secretary shall
13 estimate the amount to which a State will be entitled under subsection(a)
14 for each quarter, such estimate to be based on (A) a report filed by
15 the State containing its estimate of the total sum to be expended in
16 such quarter in accordance with the provisions of such subsection, and
17 stating the amount appropriated or made available by the State and its
18 political subdivisions for such expenditures in such quarter, and
19 if such amount is less than the State's proportionate share of the total
20 sum of such estimated expenditures, the source from which the dif-
21 ference is expected to be derived, and (B) such other information as

1 the Secretary may find necessary;

2 (2) The Secretary shall then pay to the State, in such
3 installments as he may determine, the amount so estimated, reduced
4 or increased to the extent of any overpayment or underpayment
5 which the Secretary determines was made under this section to such
6 State for any prior quarter and with respect to which adjustment
7 has not already been made under this subsection.

8 (3) Upon the making of an estimate by the Secretary under
9 this subsection, any appropriations available for payments under
10 this section shall be deemed obligated.

11 (c) Payments of grants awarded under sections 506, 507, and 508,
12 and of grants, contracts, or other arrangements under section 509,
13 may be made in advance or by way of reimbursement, and in such instal-
14 ments, as the Secretary may determine; and shall be made on such
15 conditions as the Secretary finds necessary to carry out the purposes
16 of the section involved.

17 (d) The total amount determined for payment under subsection (a)
18 of this section for any fiscal year ending after September 30, 1979,
19 shall be reduced by the amount by which the sum expended (as deter-
20 mined by the Secretary) from non-Federal sources for maternal and
21 child health services and services for crippled children for such
22 year is less than the sum expended from such sources for such ser-
23 vices for the fiscal year ending September 30, 1979. In the case of
24 any such reduction, the Secretary shall determine the portion thereof
25 which shall be applied, and the manner of applying such reduction,
26 to the amounts otherwise payable from allotments under section 502.

1 (e) Notwithstanding the preceding provisions of this section,
2 no payment shall be made to any State thereunder from the allot-
3 ments under section 502 for any period unless the State makes a
4 satisfactory showing that it is making available to mothers, infants,
5 children, and adolescent and crippled children in all parts of the
6 State health care services for which provision is made in this Act.

7 (f) Notwithstanding the preceding provisions of this section,
8 no payments shall be made to any State thereunder -

9 (1) with respect to any amount paid for items or services
10 furnished by a practitioner under the plan to the extent that such
11 amount exceeds, or is less than, the charge which is the usual,
12 customary or reasonable charge by such practitioner for such items
13 or services;

14 (2) with respect to any amount expended for inpatient hospital
15 services furnished under the plan to the extent that such amount
16 exceeds the hospital's customary charges with respect to such ser-
17 vices or (if such services are furnished under the plan by a public
18 institution free of charge or at nominal charges to the public) exceeds
19 an amount determined on the basis of these items (specified in regu-
20 lations prescribed by the Secretary) included in the determination of
21 such payment which the Secretary finds will provide for fair
22 compensation to such institution for such services; or

23 (3) with respect to any amount expended for services
24 furnished under the plan by a hospital unless such hospital has in effect
25 a utilization review plan which meets the requirement imposed by section
26 1861(k) for purposes of title XVIII; and if such a hospital has in effect

1 such a utilization review plan for purposes of title XVIII, such
2 plan shall serve as the plan required by this subsection (with the
3 same standards and procedures and with the same review committee or
4 group) as a condition for payment under this title; the Secretary
5 is authorized to waive the requirements of this paragraph in any
6 state if the State agency demonstrates to his satisfaction that it has
7 in operation utilization review procedures which are superior in
8 their effectiveness to the procedures required under section 1861(k), or
9 (4) with respect to any amount expended for indirect costs or
10 administrative expenses which exceeds 25 percent of the total of
11 Federal funds and any matching funds for the conduct of activities
12 under the State plan.

13 "OPERATION OF STATE PLANS"

14 Sec. 505. If the Secretary, after reasonable notice and op-
15 portunity for hearing to the State agency administering and super-
16 vising the administration of the State plan approved under this title
17 finds -

18 (1) that the plan has been so changed that it no longer
19 complies with the provisions of section 503; or

20 (2) that in the administration of the plan there is a
21 failure to comply substantially with any such provision;
22 the Secretary shall notify such State agency that further payments
23 will not be made to the State (or, in his discretion, that
24 payments will be limited to categories under or parts of the
25 State plan not affected by such failure), until the Secretary
26 is satisfied that there will no longer be any such failure to

1 comply. Until he is so satisfied he shall make no further payments
2 to such States (or shall limit payments to categories under or parts
3 of the State plan not affected by such failure).

4 SPECIAL PROJECT GRANTS FOR PROJECTS OF REGIONAL OR NATIONAL SIGNIFICANCE

5 Sec. 506. (a) in order to provide special incentives in
6 developing new initiatives to address problems of regional or national
7 significance, to encourage the development of new techniques in
8 resolving the problem of providing health and medical services in
9 underserved areas, to stimulate new programs and activities which
10 address current health problems and which focus upon long-standing
11 problems which have not yet been satisfactorily resolved, the Secretary
12 is authorized to make from sums available under paragraph (2) of section
13 (501(b), grants to the State agencies (administering or supervising
14 the administration of a State plan approved under section 503) and
15 to public or any nonprofit private agency, institution, or organization
16 to pay the cost (exclusive of general agency overhead for projects
17 of special programs of regional or national significance which
18 may contribute to the advancement of maternal and child health. Pro-
19 grams supported under this section may include (but are not limited to)
20 those which provide or cover the cost of the provision of services or
21 otherwise address the organization or delivery of services -

22 (1) necessary to the prospective mother and the developing
23 fetus;

24 (2) necessary to the infant during the first year of life;

1 (3) necessary to the child during the years of growth and
2 development;

3 (4) necessary for the adolescent; and

4 (5) necessary to otherwise promote the health and well-
5 being of women, infants, children, and adolescents, including
6 health education.

7 (b) Priority of grants will be given to those which will provide
8 health care services to persons who will not receive care otherwise
9 because of being from a low-income family or for other reasons beyond
10 their control. Acceptance of family planning services provided under
11 this title shall be voluntary on the part of the individual to whom
12 such services are offered and shall not be a prerequisite to the
13 eligibility for, or the receipt of, any service under such project.

14 (c) No project shall be eligible for a grant under this section
15 unless it provides for payment of -

16 (1) the reasonable cost of inpatient hospital services
17 provided under the project;

18 (2) the usual, customary, and reasonable charges of a
19 practitioner with respect to services provided under the
20 project; or

21 (3) if such services are furnished under the project by a
22 public institution free of charge or at nominal charges to the
23 public, an amount determined on the basis of these items
24 specified in regulations prescribed by the Secretary) included
25 in the determination of such reasonable cost which the Secretary

1 funds will provide fair compensation to each institution for
2 such services.

3 (d) No single grant under this section shall exceed \$2,000,000
4 in any fiscal year.

5 SPECIAL GRANTS FOR UNDERSERVED COUNTIES AND LOCAL AREAS

6 Sec. 507. (a) In order to foster the development of strong pro-
7 grams at the local level which address the health care needs of
8 women, infants, children, and youth, particularly in areas with
9 concentration of low-income families, the Secretary is authorized to
10 make, from the sums available under paragraph (3) of section 501(b),
11 with the consent of the State health agency, grants to local municipal
12 and county health agencies and any other political subdivision of the
13 State administering programs consistent with the State plan approved
14 under section 503, or to any public or nonprofit private agency,
15 institution, or organization, not to exceed 75 percent of the cost of
16 programs which provide, arrange for the provision of, or reimburse
17 for services which contribute to the advancement of maternal and child
18 health (exclusive of general agency overhead) -

19 (1) which help to reduce the incidence of mental retarda-
20 tion and other handicapping conditions caused by complications
21 associated with child bearing and to help reduce infant and
22 maternal mortality;

23 (2) which help to promote the health of preschool and
24 school age children including (but not limited to) preventive
25 services, immunizations, periodic health assessments, health

1 education, as well as other physician services and hospitalization,
2 or

3 (3) which foster comprehensive health care for youth
4 and otherwise provide for care, treatment and counseling for
5 conditions associated with pregnancy, venereal disease, alcoholism,
6 drug addiction and mental health,

7 (b) No project shall be eligible for a grant under this section
8 unless it provides -

9 (1) for the coordination of health care and services
10 provided under it with, and utilization (to the extent feasible) of,
11 other State or local health, welfare, and education programs for
12 women, infants, children and adolescents, and

13 (2) for payment of

14 (A) the reasonable cost of inpatient hospital services
15 provided under the project,

16 (B) the usual, customary and reasonable charges of a
17 practitioner with respect to services provided under the
18 project, or

19 (C) if such services are furnished under the project by
20 a public institution free of charge or at nominal charges
21 to the public, an amount determined on the basis of those
22 items (specified in regulations prescribed by the Secretary)
23 included in the determination of such reasonable cost which
24 the Secretary finds will provide fair compensation to such
institution for such services.

25 (3) that any treatment, correction or defects, or after-

1 care provided under the project is available only to women, infants, children
2 and adolescents who would not otherwise receive such care because they are from
3 low-income families or for other reasons beyond their control;
4 and no such project shall be considered to be of a comprehensive
5 nature for purposes of this section unless it includes (subject
6 to the limitation in the preceding provisions of this sentence)
7 at least such screening, diagnosis, preventive services, treatment,
8 correction of defects, and aftercare, both medical and dental, as
9 may be provided for in regulations of the Secretary.

10 (c) No single grant under this section shall exceed \$1,000,000
11 in any fiscal year.

12 TRAINING OF PERSONNEL

13 Sec. 508 From the sums available under paragraph (4) of section
14 501 (b), the Secretary is authorized to make grants to public or non-
15 profit private organizations or institutions of higher learning for
16 training personnel for health care and related services for mothers and
17 children. In making such grants the Secretary shall give special at-
18 tention to programs providing training at the undergraduate level.

19 RESEARCH PROJECTS

20 Sec. 509 From the sums available under paragraph (5) of section
21 501(b), the Secretary is authorized to make grants to, or jointly finance
22 cooperative arrangements with, public or other nonprofit institutions
23 of higher learning and public or nonprofit private agencies or organi-
24 zations engaged in research or in such programs, for research projects
25 relating to maternal and child health services or crippled children's

1 services which show promise of substantial contribution to the
2 advancement thereof. Special emphasis shall be accorded to projects
3 which will help in studying the need for, and the feasibility, cost,
4 and effectiveness of, comprehensive health care programs. Grants
5 under this section may also include funds for the training of health
6 personnel for work in such projects.

7 ADMINISTRATION

8 Section 510(a) The Secretary of Health, Education, and Welfare
9 shall make such studies and investigations as will promote the ef-
10 ficient administration of this title.

11 (b) Such portion of the appropriations for grants under section
12 501 as the Secretary may determine, but not exceeding one-half of 1 per-
13 cent thereof, shall be available for evaluation by the Secretary (directly
14 or by grants or contracts) of the programs for which such appropriations
15 are made and, in the case of allotments from any such appropriation,
16 the amount available for allotments shall be reduced accordingly.

17 (c) Any agency, institution, or organization shall, if and to the
18 extent prescribed by the Secretary, as a condition to receipt of
19 grants under this title, cooperate with the State agency administering
20 or supervising the administration of the State plan approved under
21 title XIX in the provision of care and services, available under a plan
22 or project under this title, for children eligible therefor under such
23 plan approved under title XIX.

24 DEFINITION

25 Sec. 511 For the purposes of this title, a crippled child is an

1 individual under the age of 21 who has an organic disease, defect, or
2 condition which may hinder the achievement of normal growth and
3 development.

4 OBSERVANCE OF RELIGIOUS BELIEFS

5 Sec. 512 Nothing in this title shall be construed to require any
6 State which has any plan or program approved under, or receiving financial
7 support under, this title to compel any person to undergo any medical
8 screening, examination, diagnosis, or treatment or to accept any other
9 health care or services provided under such plan or program for any
10 purpose (other than for the purpose of discovering and preventing the
11 spread of infection or contagious disease or for the purpose of protecting
12 environmental health), if such person objects (or, in the case such
13 person is a child, his parent or guardian objects) thereto on religious
14 grounds.

15 NATIONAL OFFICE OF MATERNAL AND CHILD HEALTH

16 Sec. 513 (a) There is hereby established in the Department of
17 Health, Education and Welfare an identifiable unit known as the National
18 Office of Maternal and Child Health Services to carry out the following
19 duties:

20 (1) To monitor the operation of title V in the respective
21 states to establish the effectiveness of State programs in
22 providing maternal and child health care services under that title;

23 (2) To seek to improve maternal and child health care
24 services through coordination of activities of the federal health
25 agencies in the operation of this title for maternal and child

1 health and crippled children's services;

2 (3) to develop, with the advice and assistance of the National
3 Advisory Committee on Maternal and Child Health guidelines for use by
4 States in the development of State plans pursuant to section 503;

5 (4) to develop, with the advice and assistance of the National
6 Advisory Committee on Maternal and Child Health, an organized system
7 of data collection and retrieval as a central source of information
8 related to the health of mothers and children and to the health ser-
9 vices available to them under this title for implementation of National
10 and State levels coordinated to serve national, State and local areas:

11 (5) to provide technical assistance to the State in carrying out
12 its plan (that is, through consultation, conferences, demonstration,
13 and evaluation); and

14 (6) To develop a long-range program for carrying out the purpose
15 of title V for implementation by the States on a voluntary basis,
16 including in such program provision for comprehensive maternal and
17 child health care services for all children and a designation of
18 priorities for program development.

19 (b)(1) There shall be at the head of the Office a Director of Maternal
20 and Child Health Services a Director who shall be appointed by the
21 Secretary. The director may employ and prescribe the functions of such
22 staff as are necessary to perform the functions vested in him.

23 (2) In carrying out any of his functions under this title, the
24 Director is authorized to make grants to any public or non-profit agency,
25 organization, or institution, and to enter into contracts with any agency,
26 organization, or institution, or with any individual.

1 (c) There is authorized for the purpose of carrying out the
2 provisions of this section such sums as are necessary for the fiscal
3 year beginning October 1, 1979, and each succeeding fiscal year.

4 ADVISORY COMMITTEE ON MATERNAL AND CHILD HEALTH

5 Sec. 514(a) The Secretary shall establish within the Office of
6 Secretary an Advisory Committee on Maternal and Child Health (herein-
7 after in this section referred to as the "Advisory Committee").

8 The Advisory Committee shall be appointed upon the expiration of
9 the term and charge of the Select Panel for the Promotion of Child
10 Health (hereinafter in this section referred to as the "Select Panel")
11 established by Section 211, Public Law 95-626.

12 The Advisory Committee, after reviewing the findings, the goals
13 and national plan developed by the Select Panel, shall function as a
14 continuing review body, focusing on programs funded under this title.
15 The Advisory Committee shall consider both the health care needs of
16 expectant mothers as they relate to fetal development and the future
17 of their children, and the individual health care needs of the children
18 beginning at birth and continuing through adolescence.

19 The Advisory Committee's review shall result in a continuous
20 evaluation of the efficacy and efficiency of maternal and child health
21 programs with regular periodic reports and recommendations concerning
22 the program to the Secretary. Such reports shall be compiled and
23 submitted to the Office of the Secretary annually by the end of each
24 fiscal year.

1 The Advisory Committee shall be composed of the Assistant
2 Secretary for Health and the Assistant Secretary for Planning and
3 Evaluation, who shall serve as ex officio members, and of fifteen
4 other members who shall be appointed by the Secretary not later than
5 sixty days after the date of expiration of the Select Panel. The
6 appointed members of the Advisory Committee shall be selected from
7 persons who are specifically qualified to serve on such Committee
8 by virtue of their education, training, or experience, and shall
9 include at least eight persons who are practicing doctors of medicine,
10 one practicing doctor of osteopathy, and one practicing doctor of
11 dentistry, each of whom shall be recommended by appropriate national
12 professional organizations and licensed in a State as a practicing
13 doctor of medicine, osteopathy, or dentistry. The remaining members
14 shall be representatives from the scientific, allied health, mental
15 health, preventive health, public health, and educational professions,
16 as well as consumers and representatives from state and local health
17 agencies. No appointed member of the Select Panel shall serve on the
18 Advisory Committee during the first two years of the Advisory Com-
19 mittee's existence.

20 The Committee shall select, at the first meeting of the Advisory
21 Committee, one member to serve as chairperson and another to serve as
22 vice chairperson of the Advisory Committee.

23 (b) Each appointed member of the Committee shall be appointed
24 for a term of four years, except that -

1 (1) Any member appointed to fill a vacancy occurring prior
2 to the expiration of the term for which his predecessor was
3 appointed shall be appointed for the remainder of such term; and

4 (2) Of the members first appointed, four shall be appointed
5 for a term of four years, four shall be appointed for a term of
6 three years, four shall be appointed for a term of two years, and
7 three shall be appointed for a term of one year, as designated
8 by the Secretary at the time of appointment.

9 Appointed members may serve for the expiration of their terms or
10 until their successors have taken office.

11 (c) Appointed members of the Committee shall receive for each day
12 they are engaged in the performance of the functions of the Committee
13 compensation at rates not to exceed the daily equivalent of the annual
14 rate in effect for grade GS-18 of the general schedule, including
15 travel time; and all members while so serving away from their homes or
16 regular places of business, may be allowed travel expenses, including
17 per diem in lieu of subsistence in the same manner as such expenses
18 are authorized by sections 5703 of title V, United States Code, for
19 persons in the government employed intermittently.

20 (d) The Advisory Committee shall -

21 (1) Advise and assist the Secretary in the preparation of
22 regulations for, and on policy matters arising with respect to,
23 the administration of this title;

24 (2) Consider all State plans developed for approval by the
25 Secretary pursuant to Section 503, and make recommendations to the
26 Secretary with respect to such approval.

1 (3) review the long-range program;

2 (4) advise and assist the National Office of Maternal
3 and Child Health in developing guidelines under section 513(a)(3)
4 and data systems under section 513 (a)(4); and

5 (5) perform such other duties as are appropriate in advising
6 and assisting States and the National Office of Maternal and Child
7 Health.

8 (e) The Advisory Committee shall meet as frequently as the Chair-
9 man deems necessary but not less than two times annually. Upon request
10 of four or more members, it shall be the duty of the Chairman to call
11 a meeting of the National Council.

12 STUDY ON MATERNAL AND CHILD HEALTH DELIVERY

13 Sec. 515 (a) The Secretary shall conduct a study of the Federal
14 health programs for mothers, infants and children, and adolescents. This
15 study will -

16 (1) include the collection of information about cost, ef-
17 ficiency, and the effectiveness of the State maternal child health
18 and the State crippled children programs - as well as the cost ef-
19 fectiveness and efficiency of all other Federal programs concerned
20 with the health of mothers and children;

21 (2) be charged to make suggestions on how the Federal health
22 programs for mothers, infants, children, and adolescents can be
23 coordinated if not consolidated;

24 (3) evaluate the extent to which, and reasons that, title V
25 has been unable to provide to eligible persons care for which they

1 are eligible under that title;

2 (4) make recommendations for improving the delivery of health
3 care services made available under title V to eligible beneficiaries
4 including any recommendations for bringing such care to individuals
5 in shortage areas.

6 (b) In carrying out these studies the Secretary shall invite the
7 participation of other Federal departments and agencies having related
8 responsibilities and interests, State governments, medical associations,
9 and insurance carriers.

10 (c) The Secretary shall make a report on this Study and forward the
11 report with such recommendations as he deems appropriate to the Congress
12 and the President on or before April 1, 1981.

AMERICAN DENTAL HYGIENISTS' ASSOCIATION

RECORD STATEMENT

on

CHILD HEALTH ASSURANCE PROGRAM (CHAP)
(H.R. 2159, H.R. 2461 and H.R. 4053)

for the

SUBCOMMITTEE ON HEALTH AND ENVIRONMENT

COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE

June 15, 1979

AMERICAN DENTAL HYGIENISTS' ASSOCIATION
STATEMENT ON CHILD HEALTH ASSURANCE PROGRAMS (CHAP)

The American Dental Hygienists' Association is grateful for the opportunity to submit a statement on Child Health Assurance legislation presently being considered by the Subcommittee.

Association policy has long encouraged the enactment of federal health care programs for children which include comprehensive dental health care. Of course, we enthusiastically support programs which direct health care to children of low-income families eligible to receive Medicaid assistance. However, the Association believes that any such program should include dental care as an integral part of total health care.

The effects of inadequate dental health care on children are often overlooked. Children with dental diseases often have systemic infections that are traceable to dental disease. Premature loss of primary teeth from decay and neglect can be seriously detrimental to the growth and quality of a child's permanent teeth. Loss of teeth means potential for facial disfigurement which can be socially and psychologically damaging to a child. Children with dental disease and missing teeth cannot chew food properly which may result in digestive problems as well as poor nutrition habits. Furthermore, improper care can mean that a young child must cope with dentures to maintain normal chewing and diet.

Yet, dental disease is clearly preventable. Routine preventive dental care and treatment of children can stave off tooth decay and periodontal disease which can become painful, debilitating and expensive to treat if left unattended. This last point cannot be overemphasized: preventive dental care is known to be a cost-effective health service. Illustrating this point is the Children's Comprehensive Dental Health Program implemented and funded by the State of Vermont between 1974 and 1976. This program, aptly named the Tooth Fairy Program (TFP), was directed toward children of low and middle-income families. An evaluation report of this program has now been published and the findings are significant.

The report notes that the total cost of the Vermont program was \$480,000, \$450,000 of which represented payment to dentists for dental care (80,000 services for 12,000 children). Only \$20,173 was spent for program administration. The total annual cost of the TFP was equal to 0.3 of one percent of the state budget.

The program was considered successful by the families of enrollees (97 percent recommended continuation of the TFP) and also by Vermont dentists (88 percent provided support). In a state with a preponderance of rural towns and villages, the need for dental care was substantial (48 percent of the enrollees had never received dental care or had experienced only emergency care; 32 percent of the enrollees had never received dental care).

The evaluation report further states that the Tooth Fairy Program demonstrated that dental expenditures decrease after the initial year of treatment. In the TFP, third year enrollees consumed an average of \$54 in dental services. The same group used \$69 in dental services in the

previous or second year (an average of 21 percent reduction of expenditures after two years enrollment in the TFP). Further, the program demonstrated that the rate of school referrals declined from 40 percent in 1975, to less than 20 percent in 1976.

ADHA members believe that it is extremely important for federal programs such as CHAP to include adequate provisions and financial support for oral health care and services. The current Early Periodic Screening, Diagnosis and Treatment Program which provides health care for Medicaid-eligible children, has been sluggish in providing dental care and grossly underfinanced. We are pleased that dental care is mandated in the bills now being reviewed by the Subcommittee and that the incentives to states to improve existing children's preventive dental care will be at parity with other health care services included in the CHAP. Clearly, child health can be assured only when the overall wellbeing of children is properly addressed, and oral health care is recognized as an integral part of total health.

We wish to point out a significant discrepancy between the Administration CHAP bill and the bills introduced by Representatives Carter and Maguire. This discrepancy concerns federal matching fund incentives for dental treatment. The Administration bill provides that federal matching funds to the states for dental treatment would be at a uniform rate, whether or not a child has undergone a total health assessment. The Carter and Maguire bills provide for a higher federal match to the states, if dental treatment follows an initial health assessment. The Association supports the provisions in the Carter and Maguire bills. We feel this higher federal match rate would be an important incentive for states to promote both total health assessments and subsequent referrals for needed dental treatment.

There is a second difference between the Administration bill and the Maguire and Carter bills. The income eligibility requirements of the Administration's bill would provide coverage to fewer children than those made eligible by the Carter and Maguire bills. However, we are confident the Subcommittee will recommend to the Committee on Interstate and Foreign Commerce a Child Health Assurance program that will adjust these differences fairly.

Again citing the Vermont Tooth Fairy example, the evaluation study of the program showed that projects which exhibited the following features had the greatest patient participation:

- * Convenient location;
- * Flexible hours;
- * Outreach and follow-up programs;
- * Pleasant atmosphere;
- * Seriously evaluated goals and objectives.

We would hope any implementing rules and regulations would require that provider applicants be evaluated on the basis of staff and equipment as well as these above-mentioned criteria which so contributed to the success of the Tooth Fairy Program. Such a comprehensive evaluation of provider applicants would help insure improved child health care and increased

program participation.

A primary concern of Association members in advocating a proposed Child Health Assurance program is that all children eligible for services under the Act will be reached. One of the weaknesses of the EPSDT program is the complicated and unwieldy eligibility standards. We are pleased that these standards have been significantly simplified in the Child Health Assurance proposals before the Subcommittee.

Another weakness of the present EPSDT program is that all health screenings are done by physicians and nurses who, despite their knowledge and training, are not oral health experts. ADHA endorses the direct referral concept in each of the bills that requires state health officials to maintain lists of participating dentists who will provide CHAP services.

Registered dental hygienists should be considered as part of the potential solution to the problem of access to dental care - they are academically prepared and licensed to provide preventive care and therapeutic services. Therefore, they are a unique manpower resource in the dental profession and are qualified to work with dentists in providing the highest level of preventive dental care to Medicaid - eligible children. Since many states authorize hygienists to perform preventive and therapeutic services in schools, hospitals, penal institutions and nursing homes, it would be a logical transition to incorporate hygienists in an innovative outreach program under CHAP.

It is the Association's opinion that the public health policy view encompassed in the CHAP proposals, which holds that dental care and preventive oral health services are an integral part of the total health care of the nation's children, is a sound policy. It is a policy which we believe will be endorsed by the Congress. We believe that the investment of public funds in a total preventive health care program for disadvantaged children is cost-effective insurance for the future good health of the next generation of Americans.

TESTIMONY OF
THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS

The American College of Obstetricians and Gynecologists commends the Subcommittee on Health and the Environment for its recognition of a need, and support for efforts to provide comprehensive health care to low-income children and low-income eligible women. Currently, federal programs designed to support health services for this population are fragmented and poorly coordinated at both the Federal and State level as has been documented by the Subcommittee. Subcommittee Members addressed this issue and successfully moved through Congress legislation to establish the Select Panel for the Promotion of Child Health which was realized by enactment into P.L. 95-626. We applaud this action and look forward to the Panel meeting its goal of developing a national policy for the health care of mothers and children which will serve to dissemble and eliminate overlap and administrative duplication among federal programs.

During this Congress' consideration of the Child Health Assurance Program (CHAP) proposals submitted thus far, the American College of Obstetricians and Gynecologists strongly feels that this streamlining process can begin before the completion of the Select Panel's task.

Among the Federal programs created to improve the health of this nation's women and children, the Title V Maternal and Child Health Program stands out as the first effort to attend to these needs by initiating, at the state level, a distinct administrative unit to promote the health of the maternal and child population. Clearly, the mandated intent of Title V, when it was enacted in the original

Social Security Act, was to provide grants to States for planning, assessment, and coordination of the existing health services resources present at the community, county and state level. To assure this function, each state was required to submit a state-wide plan demonstrating the state's commitment and attention to all of the above concerns. Congress extended the mandate of Title V and in the 1960's authorized additional monies for development of special projects to address maternity and infant care, the health of school-age and preschool children, as well as the dental health of these children. We strongly support such demonstration projects in the states and feel that establishment of such projects in remote and underserved areas of a state is a sensible and worthwhile approach to the promotion of health for residents of that area. However, we caution Congress to bear in mind that operation of such projects and provision of personal health services is not the primary objective of the Title V program. If Congress looks first to Title V programs to account for the numbers of women and children served per state by such projects, the state may risk losing focus on its original mandate to coordinate and assist in the administration of existing projects which can combine to supply the comprehensive services for the population in need. Title V mandates that the state program directors, who are ultimately responsible for coordination of these medical services, will be physicians and that there will be

sufficient medical and health professional staff at the state level to assure the good quality and comprehensiveness of the state program. We feel that this is a sound basis from which to build a state program.

Contrast this structure with the Title XIX mandate to serve as a health care financing mechanism for the actual provision of health services for low-income individuals and it becomes apparent that any Child Health Assurance Program enacted by Congress, which will utilize Title XIX medicaid monies for the provision of comprehensive preventive medical care for mothers and children, is not conflicting with Title V programs but instead will compliment Title V activities. To this end, we urge Congress to review these programs together.

The speciality of obstetrics and gynecology has as its primary goal excellence in the provision of maternity care for women. Inherent in this objective is the desire for quality health care available to all women regardless of age, marital or family status, or financial resources.

The combination of existing programs, health professionals working in the delivery system, and legislators working to reform inequities, are making valuable efforts to attain this objective by supporting changes in policy and behavior of health professionals, as well as their patients, which will remedy problems resulting from lack of access, acceptance and financial assistance. The American College

of Obstetricians and Gynecologists strongly supports the proposed extension contained in CHAP for Medicaid eligibility to all low-income pregnant women meeting proposed income requirements or the state income standards, whichever is higher.

The Department of Health, Education, and Welfare has estimated that because some states have limited Medicaid eligibility for pregnant women, approximately 100,000 women go without essential prenatal and postnatal care at a critical time for both mother and child. As the organization of physicians who are best qualified to provide maternity care for women, ACOG feels that these estimates -- of women who carry a pregnancy to term without ever coming into contact, or having limited contact, with appropriate health professionals -- are indeed valid and significantly demonstrate the sound argument in favor of lifting existing financial barriers. Remaining barriers which contribute to the number of unattended pregnancies must still be addressed. Geographic maldistribution of appropriate health professions is clearly a factor and needs to be approached by the profession and others, inside of Congress and out, who can work to assure quality programs in all regions of this country. In the interim, we urge Congress to address and support this extension of Title XIX which can have immediate impact upon a significant problem facing thousands of pregnant women in need of health services.

This provision of the CHAP legislation, supported by the Administration, is not new to Congress. Revision of

Medicaid eligibility for pregnancy has been proposed many times by Senator Alan Cranston, Chairman of the Subcommittee on Child and Human Development, as an effective first step in assuring the quality of health of our children. We urge that the Committee support this provision contained in CHAP and separately introduced in the form of S. 1211, in order to allow enactment during this session of Congress.

We suggest that, during consideration of CHAP and Title V revision, the subcommittee examine and consider the recommended revisions contained in a bill introduced in the 95th Congress by Congressman Rogers and Congressman Tim Lee Carter (HR. 10704) which has been supported by the American College of Obstetricians and Gynecologists, the American Academy of Pediatrics, and the American Medical Association. As major organizations representing physicians and the specialties responsible for the health care of the maternal and child population, we consider their health concerns deserving of a centralized administrative office receiving high-level priority within the Department of Health, Education, and Welfare. By mandating this reorganization and creation of a central Office of Maternal and Child Health, Congress will establish a unit able to implement the policy recommendations submitted by the Select Panel for the Promotion of Child Health. New (or perhaps it would be more appropriate to say renewed) emphasis should be placed on the development of the state plan. Over the recent years, regulations have weakened and, in fact, dismissed the requirement for states to annually

submit their state plan for Title V activities. We strongly recommend that this requirement be reinstated in the Title V mandate and that a state plan be submitted yearly to the Central Office for Maternal and Child Health which includes a state's survey of needs, present capabilities, and intentions to address the individual state's needs for additional health services for women and children.

We appreciate this opportunity to comment and contribute to your deliberations.

TESTIMONY
OF
THE ASSOCIATION OF JUNIOR LEAGUES, INC.

The Association of Junior Leagues is submitting this written testimony to affirm its support for an effective Child Health Assurance Program (CHAP) which would expand and strengthen the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program and strengthen and improve Medicaid services to low income children and pregnant women.

The Association of Junior Leagues is a non-profit organization with 229 member Leagues with approximately 125,000 individual members in the United States. Its three-fold purpose is:

- To promote voluntarism;
- To develop the potential of its members for voluntary participation in community affairs; and
- To demonstrate the effectiveness of trained volunteers.

Our commitment to effective training is reflected in the requirement that every Junior League member must participate in a training program before she begins work in her community. The majority of Junior League members continue to take training courses throughout their years of Active League membership. In addition, every Junior League member must make a commitment to a volunteer position during her Active years. A substantial number of Junior League members today sit on the boards of other voluntary organizations throughout the United States because of the leadership training which their community volunteer experience has given them.

THE ASSOCIATION OF JUNIOR LEAGUES AND ADVOCACY FOR CHILDREN

Our commitment to the improvement of services for children is long standing. Junior League volunteers have been providing services to children since the first Junior League was founded in New York in 1901. Through the years, Junior League volunteers have provided a variety of direct services to children, including the establishment of settlement houses, emergency shelters, child health and well baby clinics and have served in a variety of positions such as tutors, case aides and counselors. In the early 1970's, The Association of Junior Leagues became increasingly aware that its services could reach only a fraction of those in need. In addition, League volunteers identified many unmet needs among those children they served. A decision was made to supplement the Leagues' services by broadening the Association's activities to include advocacy on behalf of children. As a first step in its advocacy efforts, the Association in 1975 developed a study to be conducted by Junior Leagues in their own communities to determine the state of children's needs and the services available to meet them. Community surveys were conducted in 214 communities by League members trained in interviewing techniques and educated in the five focus areas chosen for the Association's Child Advocacy Program: child health, child welfare, special education, day care and juvenile justice. In the areas of perinatal care and child health, the survey results revealed a need for every woman to seek perinatal care, including good medical care and nutritional guidance. In addition, the surveys revealed a lack of facilities for monitoring high risk pregnancies. The survey also identified many inadequacies in the Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT), a preventive health care program for Medicaid eligible children under 21. Outreach for the

program was inadequate or non-existent in many areas. A great number of needy children were not reached by the program either because they and their families did not know about the program or because they did not meet their states' eligibility requirements for Medicaid. As a result of the surveys, several Junior Leagues became involved with the EPSDT program in their own communities. For instance, a survey conducted by the Junior League of Fargo-Moorhead in 1976--nearly 10 years after the enactment of the EPSDT program--revealed that the program in North Dakota had not passed beyond the developmental stages. League members identified a number of problems that had prevented the state agency from moving ahead on the program. Policy formation, organizational restructuring and personnel changes all contributed to the delay in implementation.

More than 1,000 of the some 10,000 youngsters eligible for the EPSDT program lived in the Fargo area, but there was no record of the number of the children who were actually served by the program. Members of the Fargo-Moorhead League concluded that many eligible recipients were unaware of the program. Deciding that an adequate information program about the EPSDT would increase the program's effectiveness, the Junior League of Fargo-Moorhead chose EPSDT outreach as a project.

Aware that many low income parents tend to use crisis or emergency care rather than long-term preventative care for their children, League researchers concluded that to be successful, an outreach program must do more than simply locate the parents of children eligible for the EPSDT program; it must educate the parents about the value of early detection and medical treatment for each child. Proposals for possible projects

were formulated and presented to Cass County Social Service Agency.

After more than a year of meetings with state and county personnel, the Junior League of Fargo-Moorhead and the Cass County Social Service Agency signed a contract for the development of an outreach program in which Junior League volunteers serve as mandated agents of the Social Services Agency. League members participating in the program sign personnel contracts, receive I.D. cards and when requested, attend staff conferences and state meetings concerning EPSDT procedural revision. The client's right to confidentiality is protected by having League members serve as mandated county agents with the responsibility of observing the standards set for county agents. Each volunteer is responsible for a number of clients. If a client does not respond to an informational letter about the EPSDT program, the volunteer follows up with a phone call or home visit to explain the benefits of the program and encourage a screening appointment. The volunteers take the health and social histories of each client a week before the screening occurs and keeps detailed time logs on each client. If the screening reveals a need for medical treatment, the volunteer checks to see that appointments are kept and provides transportation if it is needed. When the outreach program began in 1978, there were only two to three screenings a week in the Fargo area. By 1979, the screenings averaged more than 50 a month.

The Association's program of advocacy for children was formally launched in 1976, at which time 440 delegates from 223 Junior Leagues and representatives from 15 other organizations attended a four-day Institute on Child Advocacy co-sponsored by the Association of Junior Leagues and the Junior League of Baltimore, Maryland. With technical assistance from the Association, individual Leagues launched a variety of advocacy pro-

grams ranging from the design of parenting courses and educational campaigns on child abuse to working for legislation for subsidized adoption and foster care review systems. The experiences of individual Leagues in their advocacy programs made them aware of the need to move for reform at the federal level. For instance, many of the difficulties in obtaining health care for needy youngsters and perinatal care for low income pregnant women stemmed from federal fiscal policies that allowed states to determine eligibility on other than a strictly financial basis. In many states, financially needy children were not eligible for Medicaid because they resided in two-parent families. Many needy pregnant women were denied access to perinatal care because they were not eligible for AFDC. Especially hard hit by the limitation on perinatal care were teenagers and young women, groups with whom Junior Leagues have traditionally been involved. Moreover, aside from the factual data gathered by the surveys, Junior League members, all of whom are women and the majority of whom are mothers, have a special interest in obtaining adequate medical care for children and pregnant women. They know from first hand experience the importance of providing good health care for children and obtaining adequate perinatal care, especially during the first pregnancy when serious problems often arise.

The growing awareness of the need for change in federal policies led the delegates to the Association's 1978 Annual Conference to vote that the Association should "advocate to see that...opportunities and services essential for the optimal physical, mental and social growth of children are provided." Recently, the Association moved to fulfill this mandate by voting support of legislation in child welfare reform and child health and establishing a legislative network to secure passage of legislation in these areas. To date, 85 Leagues and 4 State Public Affairs Committees have joined this network.

PRIORITIES FOR CHILD HEALTH

As a first step toward obtaining adequate health care for children, the Association's board voted to support passage of legislation such as the Child Health Assurance Program (CHAP) introduced in the last session of Congress. We are pleased that CHAP legislation has been introduced in this session of Congress and hope that the Subcommittee on Health and the Environment will move quickly to approve strong CHAP legislation that will include the three priorities established by the Association:

- Strengthen and expand the EPSDT program, including the development of an adequate outreach program.
- Provide medical coverage for all financially eligible children, regardless of family composition.
- Provide medical coverage to all financially needy pregnant women.

We are confident that such legislation would both improve lives and save dollars. We believe it is both inhumane and fiscally irresponsible to deny children access to medical care because their parents are unable to provide it. To deny a needy pregnant woman perinatal care because she does not fit into the AFDC category threatens both her life and the life of the unborn child. Sickly children grow up to be sickly adults who cannot become productive citizens.

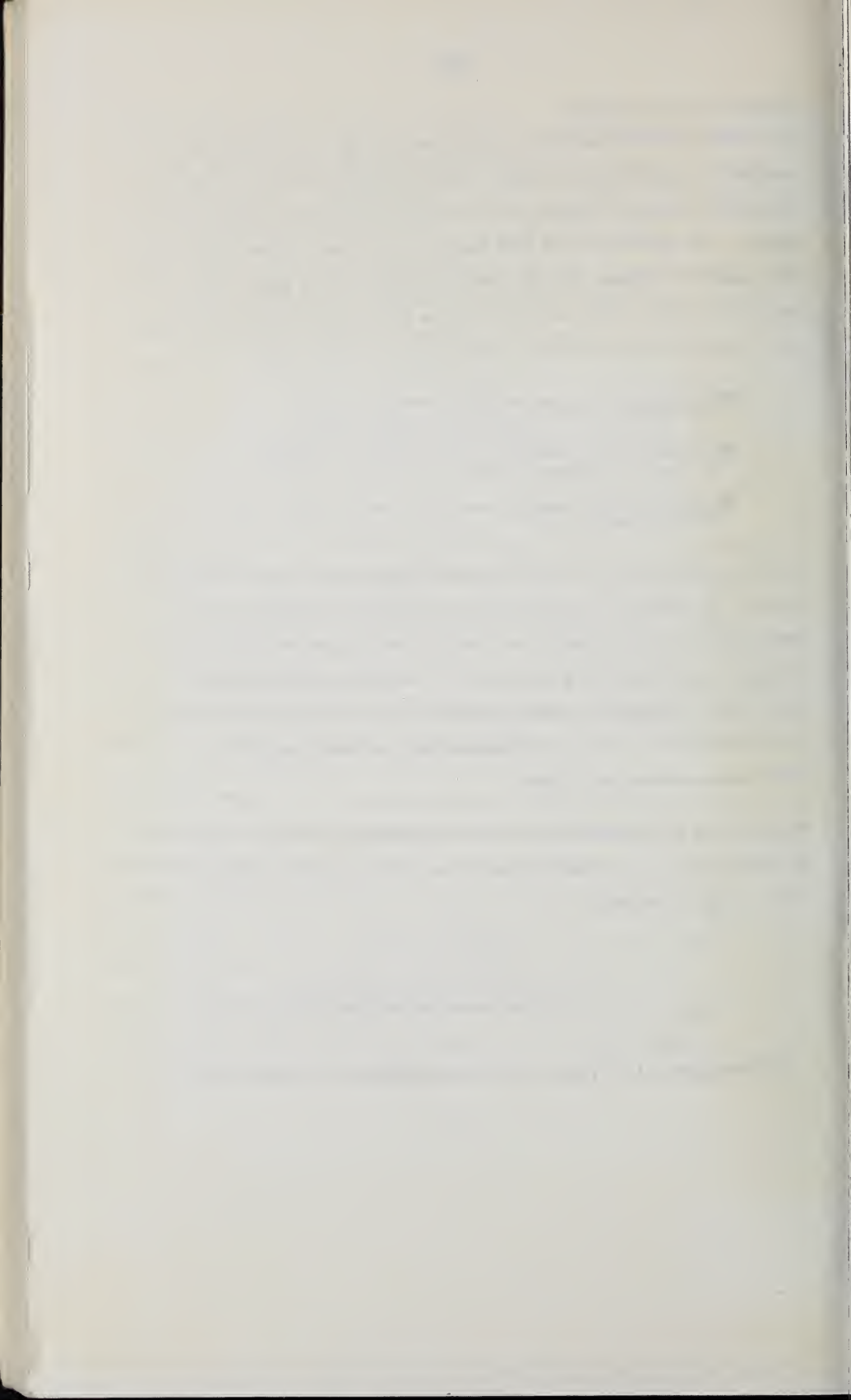
We appreciate this opportunity to submit this testimony and look forward to working with you to ensure passage of sound CHAP legislation during this session of Congress.

JACQUELYN D. BATES

Chairman, Child Advocacy Program
For the Association of Junior Leagues, Inc.

[Whereupon, at 4:57 p.m., the subcommittee was adjourned.]





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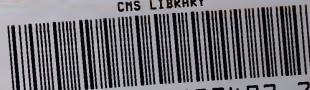
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